



DESIGN4 HEALTH

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Editors: Kirsty Christer, Claire Craig & Dan Wolstenholme

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The need for distributed co-design in healthcare contexts

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ABSTRACT *A growing body of evidence supports the notion that co-design, through a process of collectively translating experiences and ideas into physical prototypes, is vital for successful development and implementation of interventions in the challenging and complex field of healthcare innovation. Co-design sessions are usually facilitated face-to-face with participation from all stakeholders. However, the context of healthcare presents unique challenges, such as; bringing staff and patients together at the same time, staff shortages and lack of capacity, logistical and geographical barriers, rare diseases, compromised immune systems, time pressures and power hierarchies.*

For designers working in healthcare, the challenge is to overcome these complexities whilst remaining true to a co-design ethos. As such, we propose that in some cases, it can be more appropriate to intentionally engage stakeholder groups separately through distributed co-design. This paper will reflect on the process and outcomes of several case studies which take this approach, using the notion of 'boundary objects'. It will then discuss the implications of this for co-designing, within and without healthcare contexts. The three case studies are:

- *An Experience-Based Co-Design project; where staff were unable to attend due to staff shortages and lack of capacity.*
- *A PhD study focusing on spinal cord injury rehabilitation; where the designer developed separate co-design activities for staff and inpatients to allow candid discussion whilst maintaining ongoing working relationships*
- *A toolkit to improve hospital wards' use of patient experience data; where health service researchers, alongside various prototype iterations, became 'boundary objects' between different healthcare provider settings and patient representatives.*

Keywords: codesign, co-design, co-production, coproduction, boundary object

Introduction

The translation of health services research into everyday practice and widespread use is a significant problem (The World Health Organization 2005), creating what has been termed the second knowledge translation gap (T2) or research-practice gap (Greenhalgh and Wieringa 2011). Co-production, co-design and other forms of collaborative research are seen as a potential way of bridging this gap. However, they are only likely to be successful if they (a) take a systems perspective, (b) see research as a creative and human-centred endeavour and (c) pay attention to the relationships between the collaborating stakeholders, particularly in addressing power and conflict (Greenhalgh et al. 2016).

The authors have been working in the field of design and co-design within the contexts of health services research, healthcare improvement and healthcare innovation for several years. Over an extensive portfolio of experiences and case studies (Wolstenholme et al. 2014; Reed et al. 2015; Gwilt et al. 2017; Chamberlain and Partridge 2017; Wheeler, Macdonald, and Purcell 2015; Wheeler 2018; Bec 2012) we have utilised a variety of creative approaches from the array of generative methods (Sanders 2003) within the designer's toolkit. In doing so, we have come to understand that these approaches play a vital role in addressing points (a)-(c) outlined above, thereby increasing the likelihood of success.

Throughout these experiences, we have noticed a growing challenge in the ability of frontline healthcare staff to be able to join face-to-face co-design workshops. There are a variety of reasons behind this that include amongst others; a shrinking workforce and inadequate cover for staff. The vast majority of these are policy level factors that are beyond our control. However, in some, more (unusual) cases we might deliberately take a strategy that keeps stakeholders apart, perhaps due to logistical and geographical factors, rare diseases or compromised immune systems.

Collectively these strategies can be described by the overarching notion of 'Boundary Objects,' (discussed below), where the 'object' in some cases has been a space, a person or people, drawings, images or three dimensional (3D) objects (usually prototypes at various resolutions). We will use three case studies to illustrate these strategies before discussing how they fit into the concept of Boundary Objects and why this is a useful way of framing them for future co-design initiatives in healthcare facing similar challenges.

Boundary Objects

Boundary Objects were first proposed and defined by Susan Leigh Star (Star and Griesemer 1989). She described them as objects 'which both inhabit several intersecting social worlds and satisfy informational requirements of each', saying they are vague, have strong cohesive properties and are flexible and recognisable across cultures. Henderson (1991) paraphrases this to describe Boundary Objects as agents that socially organize distributed cognition.

Later Star clarified the scope of an 'object' in the current context of her boundary objects proposition. This opened these objects beyond physical artefacts to include computer programmes, spaces, theory's, drawings or even people. She stated that these 'objects' where 'things' people (or, in computer science, other objects and programs) act toward and with (Star, 2010). The notion of boundary objects has been studied further with specific reference to 'products' and to issues of knowledge 'translation' or 'transformation' (Carlile 2004; 2002).

Case Studies

We now briefly outline three case studies:

- A service improvement co-design initiative based on an acute Cardiac Ward in Bradford, UK, utilising an Experienced-Based Co-Design protocol facilitated by designers.
- A PhD study based in Glasgow, UK, focusing on spinal cord injury rehabilitation.
- A toolkit to improve hospital wards' use of patient experience data working with six wards across three hospitals in the Yorkshire region, UK.

Experienced-based co-design with Ward 22

Experience-based co-design (EBCD) is a quality improvement approach that was developed in the NHS for the NHS in 2005 (Bate and Robert 2007). The approach draws upon '...design sciences to actively engage the user in the redesign of a healthcare experience, using a co-production model, with patients and clinician's working together to create changes.' Importantly, it has been developed as a downloadable toolkit, which it claims can be carried out by healthcare staff with patients and without the need for any design expertise. Coming from a background in design practice, the lead researcher on this project became interested in exploring what might be missing without the design expertise.

The setting for this EBCD project was an acute cardiac ward in Bradford. A group of researchers on the team (including the authors), patient representatives, improvement facilitators and health services researchers carried out observations on the ward. They interviewed/filmed nine previous patients and used the footage to draw together a 'trigger film' (compiled by the designers) illustrating the entire patient journey and their emotional experiences throughout. This was presented back to the group of former patients who suggested some improvements to enhance its representation of their experience. The trigger film was then presented to the ward staff and a map of the typical patient's (emotional) journey was co-created between staff and patients. Themes for improvement were identified by all and then prioritized. From this, staff and patients self-selected the theme they personally wanted to focus on, two of which were taken forward. An improvement facilitator led one theme (focusing on discharge medications) and the designers led the second (concerning Information, Communication and Support).

The second theme ran a series of 6 co-design workshops over a course of 6 months, all of which had great attendance by patient representatives (2 at the first workshop and 4-6 in the following five sessions). However, across the course of all six workshops there was an increasing attrition of staff members that coincided with a depleted staff team (due to long term sickness, no specialist nurses on the agency staff register and delays in recruiting replacements). The final three workshops had no staff representation, so the co-design team needed to explore alternative ways of engaging the staff in the process.

To do this, the ward was visited again and a space was identified that the staff 'passed through' and paused within, at frequent intervals, for 'micro-breaks'. This space was adopted and used to put visual queries on the walls, including illustrations, provocations and prompts. Various prototypes were also placed in the space staff were invited to contribute to their development. In this way, the space and the artefacts the co-design team placed within it, became a boundary object that actively engaged the staff in the co-design process. By using this space, we were able to actively engage with a higher number of staff members, despite challenges of scheduling and staff capacity, ensuring their continued, meaningful participation in the project.

Spinal cord injury rehabilitation in Glasgow

In a recent PhD study (Wheeler 2018), both traditional healthcare-related and design-based approaches were used to explore and enhance patient participation in spinal cord injury rehabilitation. A key focus of this study was the development of a co-design process that meaningfully involved in the Spinal Injury Unit (SIU) community, including inpatients, outpatients, family members, senior SIU staff, 'front-line' SIU staff, and staff from local spinal injury charities. From a year-long, mixed-method contextual review with and within this community, this study recognised the need to protect the ongoing working relationships between inpatients and SIU staff members, which may be compromised by the (somewhat critical) co-design process. As such, outpatients, inpatients and SIU staff were engaged (in that order) separately through an iterative prototyping process. The prototypes themselves were able to elicit tacit, behavioural, experiential and/or institutional knowledge from each stakeholder group about the SIU patient pathway. This knowledge was then embodied in the development of the next prototype iteration, to be shared with the subsequent group. As such, the prototypes facilitated anonymous, creative collaboration between the stakeholder groups. This led to the development of an effective, multi-stage intervention whilst remaining sensitive to the particular needs of working in a complex healthcare setting.

Co-designing a toolkit to enable ward staff to use patient experience data for improvements

In the UK, significant resource is now allocated to the collection of Patient Experience (PE) feedback and the Friends and Family Test¹ is mandatory for all hospital Trusts. However, the overt emphasis and huge resource allocated to collecting PE data has not been matched by efforts to utilise it and evaluate its impact. In this programme of work, design principles were used as a basis for developing a patient experience toolkit that sought to address this imbalance. Following a process of creative co-design, the aim was to develop a toolkit to improve PE, rather than a toolkit to use PE data; recognizing that achieving the second aim might not necessarily lead to the first.

Participants in the co-design process included healthcare professionals (drawn from six wards across the three hospitals in the Yorkshire region), patient representatives, improvement facilitators, staff from PE teams and the researchers. Cycles of co-design prototype iterations were interjected with Action Research cycles; where the toolkit prototype was used in the wards to check and evolve the design, format and content. Whilst the initial stages of the co-design work (a series of three face-to-face co-design workshops) were used to generate prototype V1 (used on the wards in the first round of Action Research), subsequent co-design was carried out in a more distributed fashion as it was not possible to arrange any mutually convenient co-design sessions. We organised 'drop-in sessions' and developed four further prototype variations with specific test/feedback specifications that the action researchers took onto the wards. The co-design dialogue switched from being face-to-face through co-design methods to being orchestrated through the prototypes and the action researchers.

What was (and still is) significant and interesting about this project is the gradual shift in the target end user and the role of the action researchers in the use of the tool. Whilst the action researchers were initially present to *observe* how ward staff used the tool, it quickly became apparent that they instead needed to *support* ward staff in organising, structuring and analysing the PE data to be able to use it. Over the course of the five prototypes, the target end users switched from being ward staff/teams to an entirely new role, the 'PE facilitator'. The profile for this 'PE facilitator' was drawn directly from the roles the action researchers found themselves undertaking, so the end user focus of the toolkit was adjusted to accommodate it. In effect, the action researchers became a part of the prototypes.

Discussion

The arguments presented in this paper do not intend to diminish value of face-to-face collaboration in co-design activities. The benefits of which are far-reaching and well-documented. However, as discussed above, there can sometimes be value in creating a degree of separation between stakeholder groups for logistical, medical or even ethical reasons. To facilitate collaboration across this separation, we found it useful to reframe the artefacts and prototypes

¹ The Friends and Family Test (FFT) is a feedback tool that enables people who use NHS services an opportunity to provide feedback about their experiences.

created in the co-design process as Boundary Objects. This enabled us to better understand the role of design and designed materials in expanding this network of collaboration.

There is little discussion of the use of Boundary Objects in healthcare, and this paper provides three case studies that broaden discussion in this area. The first case study, using an iterative prototyping process with a range of separate stakeholder groups, corroborates the common definition of Boundary Objects as materials that carry meaning, and therefore facilitate collaboration, between and across disciplinary and hierarchical boundaries.

However, in reflecting on their rationales, methods and experiences of distributed co-design, the authors found that the parameters of the Boundary Object 'stretched' beyond the original intention and meaning. People and Space became critical elements of the boundary objects in our second and third case studies, reflecting the increasingly complex and distributed nature of healthcare services themselves. As such, the authors would encourage designers and clinical professionals to be reflective and responsive to emergent mechanisms for facilitating collaboration within their own contexts, and the wider network of stakeholders that may be engaged in future co-design processes as a result.

Conclusions

For various reasons, there is sometimes a need to consider distributed models of co-design in healthcare contexts, where critical stakeholders or stakeholder groups cannot be brought face-to-face. This makes the job of sharing any experiences and identifying relevant tacit knowledge much harder. In these cases, the visualisations and the prototypes created in the co-design process become a vital part of sharing information about participants' experiences, ideas, knowledge and insights, as well as in defining the problem to be addressed and possible solutions.

A useful model to help to frame the purpose and value of these visualisations and prototypes is the concept of Boundary Objects. Taking this idea further, we suggest that the particularly complex and distributed nature of healthcare contexts place additional demands on the co-design process, and that the concept of 'boundary object' or 'objects' can be used flexibly to include people and spaces. In each of these forms, the boundary object helps to communicate between participants across temporal, spatial, professional and disciplinary boundaries. We argue that it is particularly important for designers to pay attention to and make room for such (potentially emergent) mechanisms of distributed co-design in order to better serve the healthcare communities they wish to operate with and within.

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Moving beyond functionality and safety -Challenges in Designing AT for wellbeing

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ABSTRACT *Assistive Technologies (AT) can help people with impairments maintain independence and decrease the need for hospital care and/or personal assistance. Nevertheless, studies show that many devices are rejected, claimed not to fulfil users' needs and requirements. As part of a design project, two user studies were completed with the assumption that present AT designs do not sufficiently consider all different types of user requirements. Altogether 36 AT users were interviewed, the interviews transcribed and their contents analysed. Two main categories of requirements emerged, one concerned the 'technical whole' (i.e. requirements for technical functionality, efficiency, safety, etc.), the other the 'ergonomic whole' (i.e. requirements for comfort, usability, etc.). However, also a third category surfaced, referred to as the 'communicative whole', which included requirements for aesthetics, identity, meaning, etc. Information on these 'softer' values were found to be more difficult to elicit compared to other types of information even though fundamental for the AT not to result in negative associations and vital to address in designing for wellbeing.*

Keywords: human-centred design, assistive technology, transfer aid, user requirements

Introduction

Background

Today 15% of the world's population has some form of disability (The World Bank 2018) and with an aging population this number will most probably increase (WHO 2018). However, with support from social welfare and healthcare combined with appropriate technology, such as different types of Assistive Technologies (AT), it is proposed that people with impairments have the opportunity to live healthy, productive and independent lives (WHO 2018). AT can help compensate for limitations and postpone, reduce or even eliminate the need for care and/or personal assistance, and contribute to an overall better quality of life (e.g. Agree & Freedman 2011; Grundy 2003; Seelman 2000; Scherer and Glueckauf 2005). Nevertheless, studies have shown that assistive aids are rejected (e.g. Alper and Raharinirina 2006; Riemer-Reiss and Wacker 2000) as they do not always meet users' needs and requirements (e.g. Plos et al. 2012). Users with impairments want to 'fit in' in different social contexts but aids have been found to give rise to unwanted attention, to negative associations and even stigma (Louise-Bender Pape et al. 2002; Parette and Scherer 2004).

One type of AT involves aids for transport (e.g. wheelchairs) and aids which facilitate transferring a person for example from bed to wheelchair (e.g. sling lifts). These aids are often large and heavy, requiring space to operate and not always adapted to the use environment. In addition, the visual appearance tends to result in a 'clinical' and 'engineered' feeling.

In order to address these issues, a design project was initiated. The goal was to develop a conceptual design for a contemporary, attractive and user-friendly transfer aid to be used in different situations by different users, individually and/or with support of one person.

Aim and Approach

Two user studies were completed within the project with the overall aim to reach a more in-depth understanding of user requirements for AT and design prerequisites for acceptance and adoption. The underlying assumption was that neither present designs nor processes sufficiently consider all types of user requirements. The focus of the paper is therefore the content of the information elicited. Questions posed are: *What is the actual content of the information provided by users? What types of requirements do users verbalize? What are emphasized?*

In order to address these questions, a content analysis was conducted of the data collected in the respective user studies. The data was first coded into different themes, such as 'safety', 'independence', etc. In a complementary retrospective analysis, the product semantics framework (Monö 1997) was applied to further understand the content of the information elicited.

Framework

Monö (1997) describes a product as a trinity (Figure 1). The 'technical whole' includes the technical functions of the product, its construction and production. The 'ergonomic whole' includes everything concerning the adjustment of the design to human physique and behaviour when interacting with and using the product. The third aspect, the 'communicative whole', designates the product's communication with users and its adjustment to human perception and intellect.

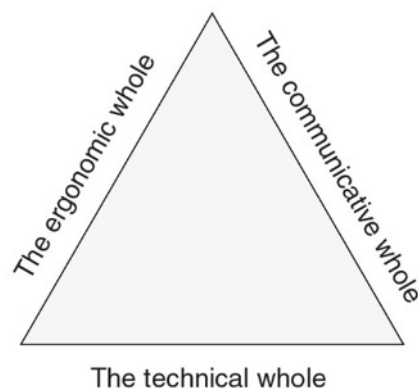


Figure 1: Monö's trinity (adapted from Monö 1997)

In line with other scholars who propose products as a language, Monö (ibid.) argues that the product, through the product gestalt, communicates a message which is interpreted by the user resulting in understanding, recognition, and emotions etc. (Figure 2).

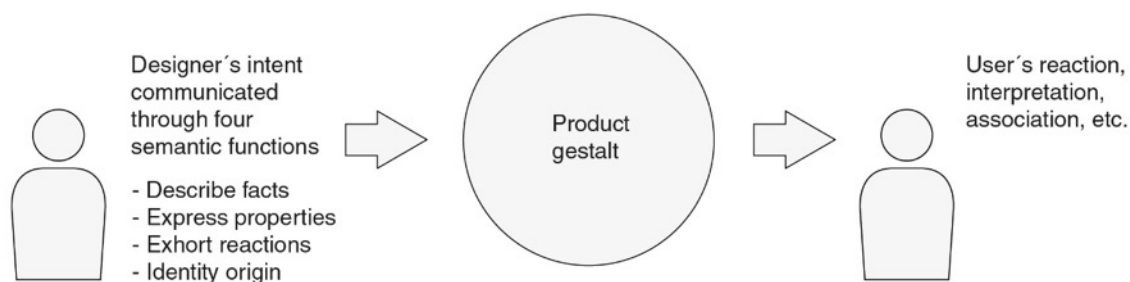


Figure 2: The message is sent from 'sender' to 'receiver' by means of the product gestalt (adapted from Monö 1997)

The message is 'created' by four semantic functions: (i) to describe product purpose and function(s), the way the product should be used and handled; (ii) to express the product's properties (e.g. stability, lightness or softness; (iii) to exhort a specific reaction such as to be careful and to be precise in the operation of the product; and (iv) to identify product origin and/or product area.

The Design Process

A prerequisite for getting financial support for the project was to be able to demonstrate a developable idea (including appearance, functionality, technical components and production method). The first phase therefore included benchmarking, ideation and concept development; the second phase a user study I, redesign, and user study II. A full-scale prototype was produced but as it did not fulfil expectations for neither technical solutions nor finish, it was not included in the user studies.

The new concept was intended to look smooth, clean but not clinical. Compared to existing aids it was possible to disassemble for transport; it had electrically powered wheels enabling one person to operate the aid with two handlebars for steering and braking; a kneeling/stretching function to adjust height and the possibility to sit astride the seat as well as turning and sliding the seat backwards/forwards to allow different positions. Technical solutions were hidden. The rear wheels were large enough to manage obstacles (thresholds etc.) whereas the front wheels were small to fit under beds, chairs etc. in order to facilitate transfers. The seat had as an option a slot to simplify personal hygiene situations.



Figure 3: Images created and used in the user interviews

The input from user study I led to several modifications to the initial concept. The 'compact' main body was modified to create an open space between the rear wheels to facilitate personal hygiene. A more traditional seat position was offered to address negative experiences of the sitting astride position. A lid was integrated in the seat to hide the slot when not needed. The kneeling/stretching function was kept but a hand control was added in order for end-users to operate the function independently. The design was thus modified in an effort to address user requirements but as a result the appearance lost some of its initial identity and became more 'engineered' in style and also more similar to existing AT transfer solutions (Figure 4).

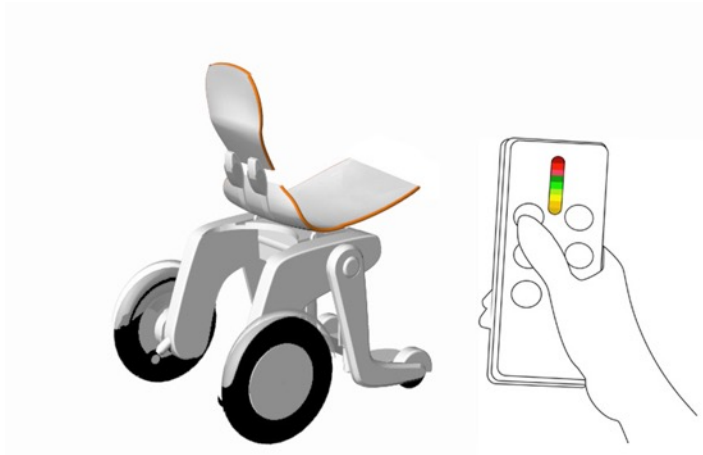


Figure 4: Image of the modified design

The User Studies

The two user studies were completed to elicit user requirements and to get feedback on the concept.

Data collection

User study I involved personal interviews with 21 participants, representing different user groups: (A) end-users, i.e. individuals with physical impairments (all wheelchair users); (B) relatives/caregivers; (C) professional caregivers; and (D) hospital staff.

After an introduction, the participants were asked to describe five typical transfer situations (from and to bed, from and to shower, etc.) and what problems they experienced. They were asked for feedback on the concept, visualized by 2D drawings and a 3D CAD model, and to reflect on if and how they were likely to accommodate the different transfers as well as their thoughts on different aspects of the aid (functionality, safety, interaction, appearance, etc).

In User study II personal interviews were completed with 15 users (of which some were the same individuals as in User Study I). Also these interviews focused on different transfer situations. The modified concept was shown, again using 2D drawings/a 3D CAD model, and the participants were asked to describe their impressions of the altered design.

Each interview lasted between 30-45 minutes, was audio recorded and later transcribed verbatim for further analysis. The location changed between private homes, cafeterias, home care units and hospital wards according to the wishes of the respective participants.

Findings

Frequently mentioned problems across all user groups concerned accessibility and related difficulties manoeuvring the aids: 'It is tight ...//... So, if you manoeuvre a big lift in it, is also not optimal.' (male, Group C)². The perceived smaller dimensions of the conceptual design therefore received positive comments: 'It looks rather neat, because many of the shower chairs we have now ... they're not that big but it's like manoeuvring a full shopping cart, it's not possible to turn' (female, Group C).

The importance of being able to manage transfers oneself was a common theme in end-users' verbalization of needs. Many thought that the new concept could lead to improved independence as it was assumed to enable transfers as well as require less physical strength during transfers. To some users, functions that were added to allow for independence carried also other positive values: 'I like these remote controls ...//... you know it's manly, like me, a whole row of remote controls.' (male, Group A). Other functions however caused concerns: 'If the wheels are power driven, then it is even more important to offer protection, because otherwise one might bang hard into a doorframe...' (female, Group A). Overall, several potential conflicts were identified between independence needs and needs for safety/security: '... It would be nice to operate it independently ...//... I would, however, feel safer to operate it with support by care-giver.' (female, Group A).

Users in groups C and D talked about the aid as work equipment, a tool for increasing efficiency and work capacity, reducing stress, and prevent work-related injuries. Some staff thought, for example that the electrical steering option would prevent back injuries but there were also those who associated the solution with unreliability: 'I tested to drive one of my caretaker's wheelchairs with a joystick and it did not work out well. So, it is why I'd rather do it manually.' (female, Group C).

Transfers associated with personal hygiene were argued as particularly important from an independence but also from a privacy perspective: 'Because you want to manage as much as possible yourself.' (male, group A). Some end-users perceived the proposed astride position as positive in that they could have eye contact with potential assistants but combined with the slot it would also leave them exposed: 'I hate it when they have those holes in the seat! It's very exposing'. (female, Group A).

End-users were more or less the only group who developed on aesthetic impressions, colour schemes, etc. They described available aids as 'un-designed' and desired something '...more personal if more visually pleasing, ... less clinical.' (female, Group A). They desired a more appealing, dignified device and the possibility for individualization in terms of choosing colours and decorative details but felt that had no saying in the matter but to get a standard version: '...take it or leave it' (male, Group A). The new concept was described as 'simple' and 'modern', but associations differed. One user associated with 'an updated shower chair' whereas another referred to a chair designed by Danish designer Arne Jacobsen: 'It reminds me of Myran, that other chair...' (male, Group A).

² The interviews were carried out in Swedish which means that the excerpts are translations.

Discussion and Implications

Users were, as anticipated, not a homogeneous group but belonged to different categories that emphasized to different degrees aspects related to the technical whole, the ergonomic whole and the communicative whole. The technical whole and the fundamental functionality of the aid were essential to all categories. Consideration to the human body and its capabilities and limitations in the design, thus the ergonomic whole, was mentioned by most but also implied different things to end-users and other groups. Finally, most end-users but less so other user groups talked about the aid in terms of what it meant and how it was understood, i.e. the communicative whole.

End-user used adjectives such as 'clinical', 'dignified' and 'modern', i.e. reflecting desired and undesired product expressions, and comments on different technical features implied that these carried meanings associated with, for example self-identity and not merely functionality. They wished for an aid to 'melt in' into their home environment but at the same time they wanted something perceived as 'cool', thus challenging previous experiences of aids as stigmatising artefacts (cf. Coleman et al. 2002). However, in comparison to information related to the technical and ergonomic whole, more detailed and in-depth information on the communicative whole was difficult to elicit.

Earlier research has shown that information on different types of needs and requirements are accessible to different degrees (e.g. Karlsson 1996; Visser et al. 2005). One explanation relates to Jordan's product pleasure model (e.g. Jordan 2000) where functionality, usability, and pleasure form a need hierarchy, the interpretation being that users must be ensured of the functionality and usability of a product (perhaps not least in the case of an assistive aid) before other values emerge as relevant. This could be understood as the 'softer' qualities of an aid are less important but this is contradicted by the end-users' quite emotional responses to different features. Such an explanation would also contradict earlier studies (e.g. Louise-Bender Pape, Kim, and Weiner, 2002; Plos et al. 2012).

Another complementary explanation is the lack of a language in addressing the communicative aspects of product design (cf. Wikström 2002). Without a language users will need support to be able to talk about and develop on problems associated with and express requirements for, for example product expressions. Searching literature, suggested examples of such support include the use of metaphors, Krippendorff's Semantic Dimensions (Krippendorff 2006) and Product Semantic Analysis (PSA) (Wikström 2002) that describes a process through which, for instance, desired and undesired expressions can be identified.

Since the use of AT is anticipated to increase, it is fundamental to be able to offer design solutions that counteract rejection and prevent feelings of stigma to enhance self-confidence and well-being among the users. Thus, the importance of, for example product expression and meaning must be acknowledged also in the design of AT (cf. Mallin and de Carvalho 2015) and designers/developers as well as for example, functions that prescribe assistive aids must become more aware of the communicative aspects of design.

AT could be described as a 'niche-product' (Plos et al. 2012) developed for a user group labelled as 'disabled people' in contrast to the able people and this niche label probably influences the meanings assigned to aids and might even reinforce stigmatic elements to be associated with them (Correia de Barros, Duarte, and Cruz 2011). Rethinking the design of AT as a powerful item to communicate status, improved abilities and independence would likely change the associations of these type of aids, modify users' self-image, and increase the acceptance and adoption whereby AT can contribute as intended to an overall better quality of life.

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MyHealth: Co-Creating Men's Health and Lifestyle Postcards

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ABSTRACT *The health of all men is a public health issue. Men with intellectual disability (ID) in particular experience more physical health conditions than the general male population. Men with ID have twice as many mental health conditions and a life expectancy more than a decade below the general male population. A refusal to seek health advice may limit male health education, increasing exposure to lifestyle risks. Some health promotional materials exist. However, dated format or inappropriate language; allied to tokenistic accessibility can result in poorly conceived, stigmatized communication methods, thus rendering important health information inaccessible. To address this shortfall of accessible information, the MyHealth project has been developed with ID experts. Consultation involving men with ID has resulted in tactile, health-information postcards. The communication design is ID led but content relevant to all men. Co-creation has shaped the design of user-sensitive, printed health information. Using concise language, care has been taken to avoid exclusive, stigmatizing terminology; improving health education prospects of the system. The tactile printed format is compact, inexpensive and independent of technology, affording ownership over periodical screen-observation. MyHealth has assembled a co-creation research community for men's health information. This community is currently in one region. The MyHealth ambition is to connect nationwide communities, to co-create user-focused content in a flexible and responsible manner. In addition to the merits of the tactile platform, variations of detail preferred by members of the research community indicate need for a supporting digital health information system. A communication system resolved to benefit the lowest capability user, may benefit the whole spectrum of users. A well-conceived system may achieve the least perceptual difference between needs of those users. This will form the next phase of development; using the co-created tactile communication design to reach the widest male population.*

Keywords: human centred design, intellectual disability, health information, male health, whole male population

Introduction

Both researchers are employed by Coventry University, within the Faculty of Health and Life Science (HLS). Paul Magee is a product designer and experienced developer of user-led solutions across healthcare and assistive technology. Working in the Centre for Innovation Across the Lifecourse (CIRAL), Paul's research develops collaboration methods with people with learning disability (PWLD) and education of service providers using empowering, co-creation methodologies. Dr Martin Bollard is Associate Head of School for Research in the School of Nursing Midwifery and Health. He has published widely in nursing journals and edited two specialist intellectual disability texts. His current research programmes include men's health and disability and psycho-social interventions for adults with intellectual disabilities.

Context of the research

The needs and abilities of people with ID are diverse. There is substantive evidence showing this population have more physical and mental health conditions when compared with the general population, such as epilepsy, sensory difficulties, coronary heart disease, depression and anxiety related disorders (Emerson and Baines 2010). Intellectual disability is typically understood to affect an individual's ability to learn and socially adapt. A range of communication difficulties, such as dysphasia, are also associated with intellectual disability and people with ID are more likely to have poor literacy levels (www.healthliteracyplace.org.uk 2018). Health literacy is essential for patient safety, self- management and effective health and social care relationships with patients, families and carers and is a key determinant of health which can impact on health inequalities (UCL 2018). Whilst within the specialist field of ID efforts are made to make health information more accessible, all health and social care professionals should consider the information they provide and the way in which they provide it, to ensure they are accessible to all groups of people, including those with ID (UCL 2018).

The widely-held stereotype of men being reluctant to seek and act on medical advice (Payne 2006), in addition to the challenge to effectively meet men with ID's complex health needs, puts the health of this group of men at further risk of deterioration (Bollard 2017). We believe the distilled health messages within MyHealth are applicable to not only men with ID but to all men and, if scaled up adopting a co-creation methodology, have the potential to develop a large community of practice promoting men's health.

Co-creation, not just consultancy

Development of user-focused information communication is seldom created in collaboration with any population, tending to remain at the discretion of a production team, itself unlikely to include the intended recipient; especially so when producing literature for the ID community. Evidence of suitably democratic engagement is scarce; suggesting that, where collaboration does occur, it is not widely disseminated (Magee et al. 2016). The author's experience (PM) has highlighted poor

comprehension of communication need, as a barrier to gaining insight from the widest audience, including those typically marginalized. Consequently, involvement where it does occur tends to be tokenistic, late in the process and resulting in little real-value to users. Collaborative creation tools have given us a vital tool to circumvent this trend- Co-creation. Co-Creation refers to collective creativity, i.e. creativity that is shared by two or more people (Sanders and Stappers 2008). The aim of co-creation is to gather rich qualitative data about the potential user journey of the product or service from beginning to end. An iterative development process identifying the users' needs and desires. Influenced by previous Co-creation with specialists in ID research consultancy (Magee et al, and c2u 2016) and specifically that of information communication design, MyHealth is led by men with ID's need for health information communication in a format that makes sense to them. An activity was devised to co-design research communication, particularly the design of the Participant Information Sheet (PIS); a document used to explain the constituent parts of a research study, c2u were able to provide clarity on the type and format of communication. A series of guidelines resulted from the collaboration and consequently, MyHealth prototype literature employed the principles shown in table 1 (Magee et al 2017):

Table 1: Design principles for MyHealth Literature

paper based (offering tactile material and discrete ownership)
clarity of content with useful detail written in lay language
short sentence structure (i.e. no more than 2 lines of text)
minimal typographic distraction (for example, no punctuation)
Small, easy to handle format (A5 booklet size as a guide)
a reply consent card, written in participant's own words

Working with a local charity that supports men with ID, Grapevine Coventry, MyHealth sought collaborators not consultants, shifting the working paradigm from a consultative focus group to engaged co-creators. An example postcard was shared with a first group of men with ID to identify their preferred health content, each noting ideas directly on mock-up postcards. Based on that specification, a revised set was shared with different co-creators from Grapevine to review the inclusion of topics. The follow up feedback helped to evaluate and reshape the printed language and visual impact, ensuring suitability for these ID viewers. At the same time, we asked co-creators to consider how this information might be replicated outside of their known community. The MyHealth postcards are used here as a sharing tool for health information, offering men the support and inclusion of a community that needs accessible health education.

Scalability

Despite ID led content, further explanation of the acronym was not selected for inclusion, perhaps self-avoiding stigma. The language is positive, not critical, gently highlighting sensitive health

issues. Information selected for the postcards is brief; a prompt to seek more detail and recognise similarities to wider community. Possibly the most powerful element of this development, is a potential engagement to a nationwide community. Despite smaller origins, it has been suggested that MyHealth formatting is applicable to other uses, such as charitable organizations, training and carer communication; from whom feedback has been positive.

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A co-design investigation into Emergency Department Waiting Rooms

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ABSTRACT ONLY In response to increased demand and limited resources, Emergency Departments across the developed world are experiencing increased strain (Lowthian et al. 2012). This has prompted a range of quality and service improvement initiatives that aspire to help Emergency Departments do more with less (Rongsheng et al. 2012). In light of this interest, this paper builds on a body of emerging knowledge (Iedema et al. 2008; Piper and Iedema 2010; Reay et al. 2017) and presents the results from a co-design investigation into how experiences might be improved in Emergency Department waiting rooms.

In collaboration with an Australian Emergency Department, this research discusses a series of short co-design “sprints” that were held with nurses, patients and emergency department staff. Participants were asked to prototype a waiting experience for an Emergency Department using materials and props provided by the research team. As the ‘things-to-think-with’ (Papert 1980), the props acted as a stimulus for participants to materialise their ideas as well as discuss contemporary problems with the Emergency Department.

This paper presents the results of these co-design workshops, and provides a platform for further design research and practice into Emergency Department design. This paper discusses the strengths and limitations of co-design methodology within an Emergency Department context, and explores the extent to which co-design workshops can act as an experimental ‘playground’ to deal with highly complex and integrated problems. Furthermore, this paper also presents how co-design can also foster an environment in which ideas about the future can be investigated (Sanders and Stappers 2012).

Keywords: co-design; emergency department; person-centred design; generative design

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Experience + Experience + Experience = Empathy

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ABSTRACT *Developing empathy for the people we design for is a prerequisite to more effective design outcomes. Intellectually we can all appreciate aging and disability. Only when we ‘experience the experience of another person’s experience’ can we begin to appreciate the very lived experience we are trying to enhance. Using low level simulations and the GERT (gerontology) aging suit, students from the UK completed activities of daily living while experiencing a range of physical impairments.*

While a relatively short immersion into disability and aging could be considered superficial, the authors believe that low level experiential simulations, together with the GERT suit could be valuable in training Industrial Design students and lead to more age sensitive, inclusive design.

This paper shares findings from a 3-day design intervention, in which five Masters level students worked on a brief to develop products which would aid companionship in mobile elders.

Keywords: empathy, aging, gerontology, disability, industrial design

Introduction

We are moving towards an empathy economy that prizes the user experience. Products and services should fulfil user expectations, make them feel valued and understood. Empathic design was born out of a realisation that consumers wanted more from their products. In the experience economy, consumers search for deeper meaning from their material possessions, the services they receive and the environments with which they interact. Function needs to be enhanced by meeting the ephemeral, emotional needs of users. Empathy can provide commercial advantage by enabling designers to realise the needs that consumers may be unaware of or unable to articulate. Its strength lies in raising awareness of 'what makes life rich, personal, and meaningful' (Postma et al. 2012, 70). Although the world and the consumer landscape are changing along with a need and increasingly, legislative requirement, to design for those with different abilities, companies have been slow to adapt. Ageing consumers have been excluded by design - they are knowledgeable, discerning and wish to enjoy life to the full and they have disposable income. For example, in the UK 11.9 million people have disabilities with a disposable income of £80bn (\$112bn) a year. Saga's strategy director, Tim Pethick (quoted in Oxlade 2014) said: 'People are living longer and have more active social and economic lives, which is changing how we think about 'retirement''. The meaning of disability and aging is changing, as it does not necessarily mean dependent living, fragility or cognitive decline (Loe 2011).

McDonagh and Denton (2000) introduced the term 'empathic horizon' to indicate a designer's ability to empathise beyond the characteristics of their own group, such as nationality, background, age, gender, culture, experience and education. Fundamental to this research is the belief that this horizon can be expanded by training and experience. An ageing population requires designers to reach further into their understanding of what it means to be human.

Most undergraduate design students tend to be able-bodied 18-24-year olds with 'limited life experience' (Moody et al. 2011). They begin by basing their design decision-making on their personal perspective (e.g. designing for themselves), but may continue to want to design exciting, innovative products for people like themselves. Following graduation, they will be required to design for 'the other' and hence need to be provided with the skills to enable them to do this.

To do this, they need to amass research approaches, techniques and tools to help them elicit specific information to support their design-decision making. They need to be agile, resourceful and skilled at recognizing patterns in behaviour, anticipating future behaviour and be mindful of peoples' needs, whilst not allowing the data/information to dampen their creativity (McDonagh 2015, 422).

The design community has an opportunity and responsibility to contribute to the quality of life for all. Looking at the need to encourage independence in old age, there are issues in the degree to which user centred design approaches have been used successfully to inform the design of assistive technology products (Woodcock et al. 2013; Scott et al. 2015). These may still not be designed with a recognition of end user needs. For example, products may be designed to

accommodate decline or disability in one function, but not associated ones; the context of use is not recognised (i.e. the home environment and personal circumstances of the end user); higher level, 'belongingness' needs are neglected (Maslow 1943); or designers do not have the right tools to understand users with specific, critical and additional needs (Scott et al. 2015).

Key questions relate to how we can help students to design for the 'other' – so that they have the most appropriate tools and mindset to deal with requirements of older consumers. Student design briefs typically require students to design products for the mid future meaning they simply project their current selves into the future, and design 'technocentric' products without considering how usable such products may be in futures in which they might be disabled or disempowered. The current, tangible, everyday problems of older users are ignored (e.g. not being able to read prescriptions, open water bottles or medical packages, or walk downstairs) and a complacency is created. In her 2012 paper addressing the needs of laggards and late adopters (who form over 48% of potential users), Woodcock, concluded that there was a need for student designers to have:

'greater empathy with end users, more challenging design briefs and topics and courses which are structured and allow time for in depth study, and research led design briefs' to 'increase the awareness, ability, understanding and interest of future designers in not just shaping products, but the world'. (p.58)

The Felt Sense

The authors propose that in order to address the gap in knowledge of the user, designers should develop a *felt sense* for that person through a *felt experience*. This will lead to empathic understanding.

One has to leave behind one's own context and understandings to imaginatively project oneself into the Other's situation in an attempt to see the world through their eyes. (Finlay 2005, 278)

The only way to experience a person's experience is to truly experience it (Pullin 2009). Without this, one is only able to intellectually appreciate the experience. Understanding the needs of the people you are trying to serve (e.g. carers in assistive living communities, family members looking after their elders) transitions from an abstract concept to a felt sense, when one can experience the experience.

One way of expanding design students' empathic horizons may be through the use of experiential simulations. To explore this, the authors have utilized a range of low-level experiential simulation technology tools and a higher technology system to provide students with the opportunity to experience *instant* disability and age-related impairments. This paper reviews a three-day design intervention with five masters students (specializing in transport design) at Coventry University, UK.

Felt Experience: Research Approach

The design brief was to develop products which would enable greater companionship in mobile older people. Keeping mobile for as long as possible is seen as key to maintaining good health and a high quality of life in older age. However, with failing faculties and mobility it may become increasingly difficult to form companions, or to engage with relatives and carers while being mobile. For example, wheelchair users find it difficult to talk to people who are pushing them. Although they are 'out and about' they may still be isolated and have little opportunity to converse with others. The MA students were given a brief to develop concept designs which could increase companionship. To help them address the design brief several innovative methods were used to enable them to understand the difficulties of older people, and hopefully to increase their empathic horizons. All students received payment for their participation. The stages were as follows:

Day 1. Students were introduced to 'empathy' with a motivational lecture (delivered by the first author) and familiarized with the cognitive, psychological and sensory changes that accompany ageing. After they were informed about the various stages of the workshop, they were asked to share their expectations of the three days on Post-it notes. Their first activity was to form pairs and draw portraits of each other using their feet (refer to Figure 1) to help them realise the need to leave their own selves aside and try to cope with unfamiliar situations. This activity also acts as an effective skill leveller and ice breaker. The unique nature of the activity provides an 'even playing field' for all regardless of design ability and previous experience. The students found this task physically challenging and appreciated that existing drawing tools are not appropriate for people with limited dexterity.



Figure 1. Examples of the student portraits utilizing only their feet

This exercise was followed by a mind mapping exercise in which students were asked to create mind maps about a grandparent or older parent illustrating their activities, difficulties, hobbies and needs. Students presented their initial concept ideas, in relation to the design brief. At this stage solutions were extremely techno-centric (e.g. bionic glasses, object recognition/sensor technology to aid movement and face recognition).

Students then took part in low fidelity experiential simulations to support empathic modelling (Figure 2). This allowed them to experience a disability and how it effects interaction with others. Materials included

Glasses: simulating a variety of conditions, such as, glaucoma and cataracts;

Ear plugs and tinnitus headsets: to reduce hearing in one or both ears;

Masking tape used to tape thumb and forefinger together on dominant hand, and bind three fingers together on non- dominant hand;

Thin gloves to reduce sensation in hands.

Experiencing more than one impairment, allows an appreciation of the multiple layers of complexity and challenges aging related disabilities pose. Overcoming one impairment and/or disability (e.g. reduced hearing) can be accommodated relatively easily for the average person, but when experienced another disability, the compounded impact is greater.



Figure 2. Empathic modelling with low technology aids (playing cards and phone interaction)

Students were asked to undertake everyday tasks in the low level experiential simulation such as reading labels/opening packages, putting on plasters, taking off shoes and asking their peers to put them back on, finding badges and eat with reduced vision, hearing, mobility and tactile impairments. Moreover, they were also asked to help their student colleagues in wearing shoes or communicating a task of finding destinations using their mobile phones and emailing these to the tutor and using the toilet.

Working on the design briefs during the afternoon, showed that some students had more awareness of the needs of the older people and the problems of multiple disabilities, e.g. there was a move towards considering form/shape of designs.

Day 2. Students attended a short lecture about disability and ageing and the fact that designers did not typically engage with market sector. Students agreed that this was the case, and that it could open up new design opportunities for them. To reengage with their design brief, they were asked to draw their grandparent and to think how they would engage with the product they were

designing. For some students this was a key task as they reflected that their initial ideas might not be fulfilling a need in that person's life e.g. for companionship. New designs started to emerge e.g. looking at dog walking, design of walking sticks.

Making use of higher technology for simulating ageing was made possible through GERT gerontology suit exercise, where beside physical restrictions such as poor vision and impaired hearing ability, students also faced discomfort due to mobility impairments. As the focus of the project was mobility related, students took part in a 'walkabout' where they were required to perform different activities involving getting into a car, grocery shopping, walking in a park. A companion looked after the students and photographed important moments. Most found it difficult to get into the car, adjust the seat and close the door. For reflection purposes, students were given note sheets to record their thoughts before, during and after the experience. Students were asked to evaluate their mind maps against their GERT suit experiences to refocus them on users' experiences and the design brief. Each student was requested to consider the experience of aging they had experienced in the GERT suit and produce five mood board images (e.g. abstract visuals that communicate emotions and feelings) accompanied by five keywords to sum up their understanding.

Day 3. The students stepped back into the role of designer, to deploy the new insights into the current design task. All adjusted their designs and added more details as a result of their experiences, for example by placing more attention on joint movements and pressure points. Their better understanding of what might work for people with impairments and disabilities helped them to come up with more appropriate design solutions.

Case Study: One Student Example

The mood board of one student, which highlighted the feelings she experienced when using the GERT suit and low fidelity simulations is shown below. Although this may be considered as portraying a negative view of aging, it shows that the experiential simulations led her to consider what it might feel like to be 'trapped' inside an ageing body.

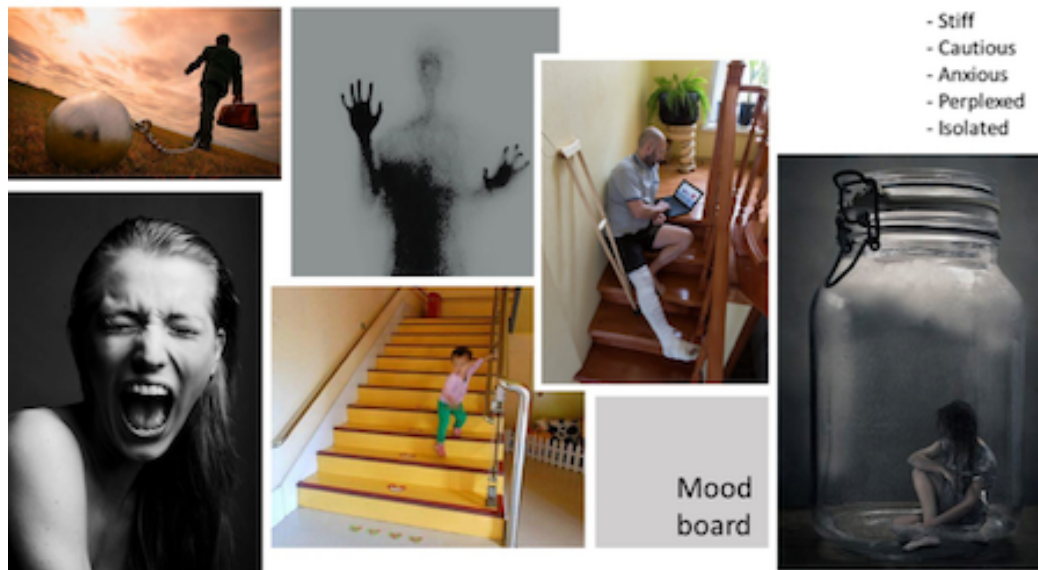


Figure 3. Example mood board expressing 'ageing'

Her final concepts revealed a more empathic understanding of the needs of elders and a more thoughtful approach (refer to figures 4 and 5 below). The first image shows a design for a walking stick handle, which is based on a handshake – representing trust, companionship, and human connection.

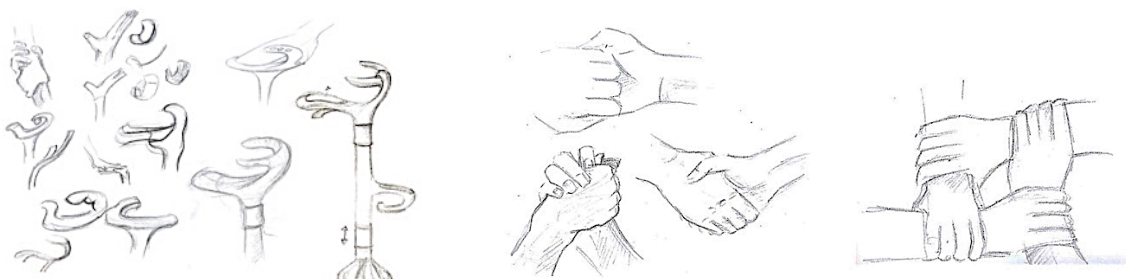


Figure 4. Movement in design direction following empathic modelling (left) initial sketches prior to empathic modelling and (right) more refined concept of gestural hand support.

The second concept (Figure 5) was for shoes which opened up, like a clam, so they were easier to put on and take off. This could be traced to the difficulties the students experienced in the low fidelity simulation when they had to remove their own shoes and help put on someone else's. This task was designed specifically to show the problems elders have with these everyday tasks, and the problems older partners may have in helping partners, when they might also have a disability.

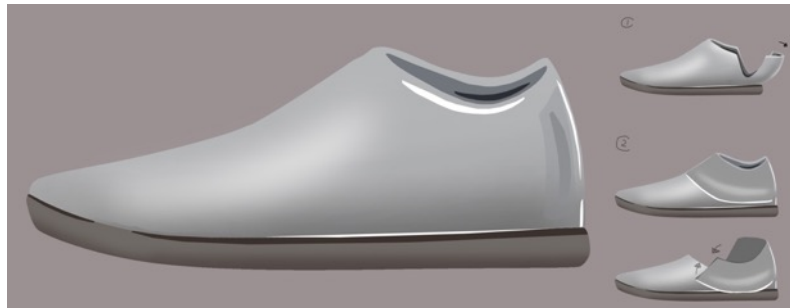


Figure 5. Initial designs for the 'opening shoe'.

Discussion and Recommendations

Despite initial scepticism regarding the value of using low fidelity simulations, the majority of students acknowledged that empathic modelling had helped them to acquire a new perspective on the experience of elders. These experiential learning exercises highlighted the vulnerabilities of older people when they experienced impairments and disabilities themselves. None of the students had undertaken this type of activity before.

In design classes, there is a tendency for students to jump to technology driven solutions with little or no consideration of the users' technological competence. Reducing their competence shows how isolating and exclusive technological solutions can be. In this case we were looking at age related reduction in competencies – but similar situations prevail against hard to reach/vulnerable groups at all ages (e.g. with respect to literacy and communication difficulties). Students need to slow down, and reflect, giving adequate time to explore and develop the problem solution space rather than rushing to a technological solution or onto CAD. In the authors' experience those students who go straight to CAD tend to produce less empathic and less intuitive design solutions.

As with our previous study, students declared that they valued the insights developed and intended to integrate the approach into their professional practice (Woodcock et al. 2017). Empathic modelling helps to expand the designer's toolkit and focuses the attention on the user they are aiming to serve. As with any tool, it is equally important for the mind set to shift from designer-centric to user-centred. Ideally integrating the experience of the user provides context and transforms the activity from abstract to real, which tends to lead to more relevant design solutions based on real user needs.

Acknowledgements

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Smart technologies in buildings: exploring the conflicts and opportunities for health and wellbeing

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ABSTRACT ONLY Throughout architectural design practice, process and research, there is motivation to develop a greater understanding of the interactions between people and their environments. Learning from previous built environments is vital in creating buildings that better respond to the needs of users. However Post-Occupancy Evaluation (POE), the current method of obtaining feedback on a building's performance in use, has major limitations in regards to understanding human building interaction (HBI) and User Experience (UX). There is a recognised need for tools, methods and techniques of user engagement in architecture. How do we evidence success in building design? In building design, what are the conflicts and opportunities for health and wellbeing? In the field of Human Computing Interaction (HCI), the development of user experience techniques to support practice and industry are continually evolving. With a lens of HCI, a research question has emerged for design evolution of built environments: What tools, methods and techniques of user engagement could be adopted from the digital realm to enable architects of the physical world, to understand user experience. The built environment is increasingly being designed to include context-aware automation (such as Smart-lights, Chromecasts Smart elevators and powered assisted doors). This paper focuses on analysis of emerging 'smart' care environments, specifically designed for a dynamic and diverse population. It will link research and practice across these contexts by creating a basis for moving forward, where themes of common interests, methods and techniques will be uncovered. Methods of building site visits, case study, observation, and interviews with the client and designers of case study buildings are presented. Discussion interrogates the potential of Digital Technologists and Architects working together towards developing methods for better understanding Health, Wellbeing, Enablement, Experience and Technology in buildings.

Keywords: Smart Buildings; Architecture; Wellbeing; Design Process; Human Experience

Becoming authentic: embracing rogues, mavericks and rebels in the co-production of boundary objects.

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ABSTRACT *This paper provokes debate about what it is that makes something a boundary object (or not). A new theory of boundary object emergence is presented, exploring the role of those on the fringes – the mavericks and rogues, in their co-production.*

The American sociologist Susan Leigh Star once commented that even her cat Watson, "is a cyborg" (p. 8, 2002). Star was referring to the way in which humans, animals and machines have become tightly entwined, blurring the categories between organic and mechanic. Our relationship with the material world has become so intimate that the usual conventions no longer apply. In this paper, I approach the human/object relationship from this perspective, showing how boundary objects - those things and ideas which are shared between different groups to provide a common language, can also be thought of as the progeny of the people who create them. I argue that it is time to move away from a structural conceptualization to focus on a set of inherited action-based properties. By focusing on these properties we are able to distinguish a 'boundary object-in-theory' from an authentic 'boundary object-in-use.'

Keywords: authenticity, boundary object, bricolage, co-production.

Context

Boundary objects are shared things or ideas that enable communication between different groups (Star 1989; Carlile 2002). One of their critical features is that they are inherently flexible but retain sufficient detail to be recognizable across different contexts. Their potential to provide a catalyst for collaboration has ignited interest across education, health, and new product design (Fujimura 1992; Wenger 1998; Carlile 2002; Allen 2009). However, despite what is known about their function and structure, designers have struggled to recreate effective boundary objects (Atwell 2011). The problem appears to be that those things intended as boundary objects fail due to a loss of intrinsic flexibility and a lack of value amongst users (Henderson 1991; Atwell 2011).

Methods

In this paper I explore resonance, convergence, and meaningfulness as defining properties of authentic boundary objects-in-use developed as an outcome of qualitative case study of university-health service partnerships. To these I add resilience, a property which represents an object's tolerance of change. How these are bestowed is a question of approach and engagement in the co-design process. Who are these individuals whose traits we wish to capture and replicate within a non-human object, and how can this be done? Designers have struggled with producing designated boundary objects, time and again finding a disparity between what is intended and what is actually used 'in real life' (Atwell 2011). Emphasizing the theme of human/non-human relationships, I suggest that it is crucial to engage people who possess certain traits which drive and define the final co-produced object.

Findings

Bricolage is both a process, and an outcome. In bricolage, old materials are used for new purposes. Bricolage holds relevance when it comes to the creation of boundary objects as it is through this process that the traits of the bricoleur are imparted. Levi-Strauss (1962) described this as the way in which an object created through bricolage carried something of its creator with it. Bricoleurs are those individuals who engage in this repurposing. They are characterized by a willingness to improvise and experiment, deviating from formal procedures. This readiness to subvert means that bricoleurs are often perceived as non-conformists who challenge the status quo. I suggest that these 'marginal people' (Star 1989) are instrumental in the creation of authentic boundary objects-in-use. If we are to design and develop truly useful boundary objects then we must seek out these rebels, mavericks and rogues. Identifying and engaging such individuals could present a challenge. I advocate an approach combining tactics of cool-hunting alongside assertive outreach to target and attract those operating at the fringes of our organizations. Their inherent flexibility, resilience, and readiness to improvise represent both the skills required to instigate bricolage, as well as the traits we wish to capture and replicate within the final object.

Discussion

Capturing the traits in others that we wish to be represented in the things we make and do is akin to a process of inheritance which can drive the evolution of more authentic shared ideas, things, tools, services, and products. Boundary objects are inherently 'of us'. Recognizing this enables us to approach their creation with a more nuanced sense of co-design. Engaging those individuals whose traits we wish to instil in such objects means that the final finished object is resilient, meaningful, represents the convergence of multiple viewpoints, and possesses resonance because of this. Together these properties contribute to a level of authenticity which appeals to users.

Conclusion

I propose that the most effective boundary objects are those which are co-produced through a process of bricolage, during which specific traits are inherited from their creators. This idea of transmission and inheritance dovetails with evidence suggesting that boundary objects reflect embedded social meanings which influence their appeal and uptake amongst users (Fox 2011).

The collision of convention with non-conformism, of investing human traits in objects provokes difficulties at an individual and organizational level. Bricoleurs as rogues naturally operate on the fringes, forgoing the formal to do things their own way. They can defy hierarchy, can be difficult to manage, or elusive in disclosing their methods. This can sit uneasily within the context of large, hierarchical organizations such as the National Health Service. The challenge is compounded by another more ontological debate: by yoking the maverick do we automatically clip her wings? Is it possible to reconcile the rogue with the robust? I argue that the only way to discover whether authenticity can be instilled through bricolage is to embrace the mavericks and start experimenting. Can the ghost be embedded in the machine in this way?

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The paradox of personalising wearable health design: from ostomy to fashion accessory?

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ABSTRACT *This research paper explores the challenges of combining personalized design approaches with industrial production of wearable health devices, which are associated with taboo, stigma and a need for discreteness. Current research states that becoming a user of a wearable medical device significantly compromises the sense of identity (Kelly 2014). Jacobsen (2014) demonstrates that assistive products are considered material for defining, constructing, shaping and expressing the self. Responding to this, several scholars call for a need to address individual wearable health design (Royeen 2015; Bush 2015; Pullin 2009). Based on a case study of the Danish medico-company Coloplast's development of SenSura Mio, a design-awarded ostomy bag created for individual fit, the paper presents how the designer involved was highly inspired by fashion and textile design to work with ostomy wearers' sense of self. Involving feedback from wearers of SenSura Mio ostomy bags, the case conveys how personalized design could contribute to individual qualities by exploring how functional and expressive drivers can heighten the experience of wearing an ostomy bag. The paper finally discusses if an ostomy bag can be considered as a fashion accessory?*

Keywords: sense of self, personalized design approach, wearable health design, taboo, fashion accessory

Introduction

Taboo is defined as something that is avoided or prohibited for social reasons³. Such reasons vary, but when it comes to ostomy care⁴, they often relate to ignorance of disease and functions or situations concerning body waste, which are shrouded in stigma because of their intimate and personal nature. Functionality and discreteness are therefore key design parameters for ostomy wearers. Product design for this particular target group serves as an interesting case study because what is involved is actually the wearers' sense of self (Bendix 2016).

This paper presents different wearer perspectives and current product development, in particular Coloplast's design award winning ostomy bag. The SenSura Mio is highly inspired by textile and fashion design to create a wearable health device that fits individual needs. It is an attempt to frame the challenge of using personalized design approaches to industrially manufacture wearable health devices. To critically reflect and raise new questions, a three-hour workshop facilitated new perspectives of a former stoma nurse, the former designer of SenSura Mio and a person who wears it. Finally, the paper encounters these insights in a concluding discussion.

Designing health wearables in the area of taboo, stigma and discreteness

'Wearable wellbeing' is a term coined by Bush (2015) concerning designed health objects that are habitually worn by persons and extend beyond a focus on the medical body. This notion might have been the starting point as well as the final goal for Coloplast's re-design of SenSura Mio (Figure 1).

³ <https://dictionary.cambridge.org/dictionary/english/taboo>

⁴ The term stoma refers to a surgically created opening in the body for the discharge of body wastes. Different diseases (e.g. cancer, Morbus Crohn, etc.) in the abdomen area can require an operation causing the need for an ostomy bag.



Figure 1: The design development of Coloplast's ostomy bags since 1957

What is particularly notable in the design is the change of material and colour. Since the foundation of the company, it has refined its products also to include underwear for ostomy wearers. This led to a radical shift in the focus of the company (Meyer 2016). Working with textile designer Astrid Krogh and fashion designer Anette Meyer in developing underwear with a high stretch-ability, the partnership included a personal design approach for the product to look like ordinary underwear.

In 2009, Coloplast hired industrial designer Jakob Bendix to help develop a completely different product line in the ostomy area. Interviewing him, while he was still employed at Coloplast, his viewpoint on what he was creating was *appealing* products (2016). Interviewing him in 2018, he has now left the company and is therefore interesting due to his experience, to bring into play the questioning of whether an ostomy bag can be a fashion accessory.

The design process of SenSura Mio

The first thing Bendix told in 2016 was that Coloplast included non-users to clarify existing product associations, only to find that both colour and material needed to change dramatically as the existing devices had 'Prosthetic aesthetics'.

To develop a premium feel, Coloplast started to experiment with other materials instead of the traditional non-woven fabric, which is an industrial, medical and foremost cheap see-through material. One could argue that this effect does not radiate discreteness for the wearer.

Bendix also started to do design explorations with new colours (2016). Using physical prototyping methods instead of 3D renderings on a computer gave him insight into the material qualities and how different colours appear underneath various clothing e.g. under a white shirt (Figure 2).

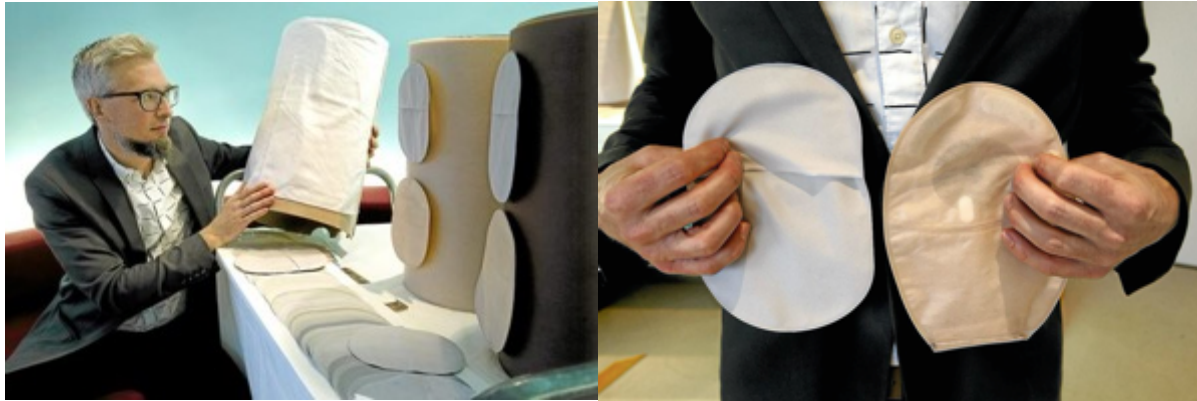


Figure 2: Bendix tests different grey colours underneath white cotton to see which tone of grey is less likely to reflect shadow back onto the skin of the wearer

Focussing on the wearers' sense of self led to the opportunity of aesthetic choices in the design process, especially to emphasize lifestyle perspectives of having a stoma. Furthermore, Coloplast starts to portray the persons with an ostomy differently in their marketing material. In Figure 3, a man stands in his bathroom with, among others, a bathtub with a Vola fixture designed by Arne Jacobsen.



Figure 3: Image from Coloplast's marketing material

The wearer is getting ready for what is probably another day in the office. His ostomy bag blends in with the colours of the interior and is purposely, according to Bendix, designed in grey to be discrete (2016). He explained that the colour he chose in the end was the result of an interminable experiment with pens and black ink. With dye dip techniques, also used in textiles design, Bendix tested several nuanced grey samples of textiles upon white cotton before he was finally able to produce the most suitable grey nuance of SenSura Mio, a technical detail Coloplast has now patented.

Can an ostomy bag be a fashion accessory?

Coloplast's design approaches and the creation of the object SenSura Mio trigger thoughts of accessory design methods and practices. Jack Cunningham (2005), who is a researcher and maker of contemporary jewellery, is of interest here as he enrolls a set of relationships between the maker, the wearer, and the viewer when designing accessories for the body. Similar to Bendix's relation to the wearers' sense of self, the ostomy bag can be seen as an accessory for the wearer as they are both intimate objects carried closely to the body. It is therefore interesting to explore what the similarities are between accessory design and SenSura Mio. So, I presented these questions to wearers of SenSura Mio to reflect how Bendix's design, inspired by fashion and textiles design and similar to accessory design, contributes to individual design qualities for the wearer.

Questionnaire

An online questionnaire was posted in a Danish ostomy community in a closed Facebook group. The aim was to explore if both functional and expressive drivers can heighten the experience of wearing the SenSura Mio. In previous findings, Møller and Bang (2016) identified the nature of the accessory as:

- A carrier of the wearer's identity
- Embedded with personal and emotional stories
- A symbol of significance to the wearer
- A conveyer of stories about the wearer and reminder of whom the wearer is
- An integrated part of the wearer
- Having bodily qualities
- Having emotional, memorable and material value to the wearer.

18 participants ranged from the age of 23 up to 69 - 16 women and two men, filled in the questionnaire.

Analysis

When asked about three things the wearer thinks of as inherent qualities of SenSura Mio, several different associations appeared. Words as 'ethical pretty', 'unique', 'applicable', 'discrete', 'soft', 'nice look', 'nice to touch', 'neutral' and 'light',

One person states that apart from the colour, SenSura Mio looks like other ostomy bags. Another feels insecure about the 'lightness' because of the 'thin' product, whereas one highlights this as a good quality. The insights gathered from the questionnaire show that all 18 participants are very individual.

When asked if they think that SenSura Mio is designed to match their identity, 44.4 % disagreed (Figure 4).



Figure 4: Screenshot from the Google questionnaire on the question if the wearers think SenSura Mio is designed to match their identity

The negative answers written after the opportunity to mark no highlights that almost 50 % of the participants think that SenSura Mio is a design that has to fit all. One writes:

'My ostomy bag has nothing to do with my identity. It is a practical measure that just simply has to work!'

Two of the participants write that the question is odd, and one follows up with this reply:

'I suppose it is designed to be as discrete as possible and fit the surroundings of the ostomy to avoid leaks and skin issues. That has nothing to do with identity.'

The next question raises a similar concern, and here 61 % of the wearers think that SenSura Mio is designed to fit their personal preferences. Some of the notable replies are:

'It works, and I trust it, so I do not have to think about it except when I have to change it.'

Another replies that SenSura Mio is a little more elegant than other ones the participant has tried.

In return, a response was that the participant is confident that SenSura Mio is designed to fit all which is an interesting dilemma, due to insights of Bendix's inspiration and exploration towards choices in regards of the material, colour, overall finish and aesthetics.

Takeaways

Analysing the participants' replies to the question of whether the design of SenSura Mio is of importance to them, I start to feel uncomfortable as I go through the questionnaire answers. My

sense of discomfort is both due to personal embarrassment but also an unfulfilled interest into what is going on when you are an ostomy wearer. How can you even propose to compare the qualities of accessory design with the qualities of a person's ostomy bag? This makes me start to explore persons with stomas that deal with their condition out in the open, putting aside taboos, stigma and discreteness.

Public Ostomy Wearers

Getting access to the closed forum COPA on Facebook I see that several ostomy wearers show images of their ostomy bags, daily challenges and obstacles. There seems to be a tendency, especially on social media, for ostomy wearers to share their 'everyday life' openly. Danish Astrid is one of them (Figure 5).

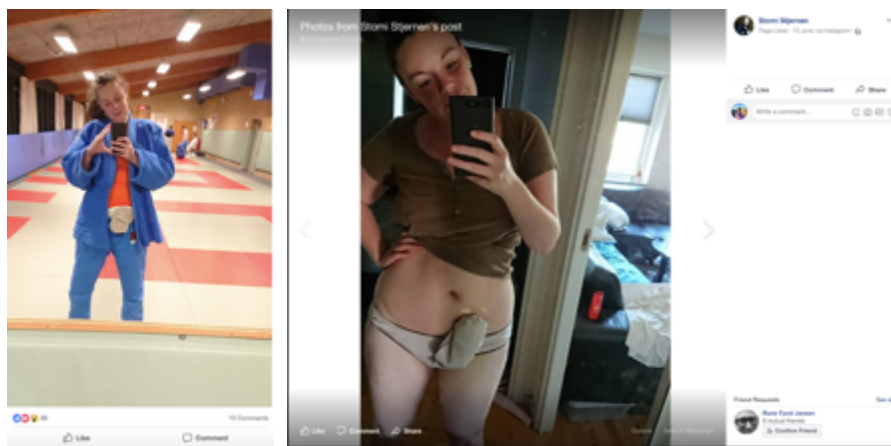


Figure 5: Astrid and her public life on social media

Since her operation in 2017, she blogs⁵ openly about her everyday challenges and issues, and on Facebook and Instagram⁶.

⁵ <https://stomistjernen.wordpress.com/>

⁶ <https://www.instagram.com/astridboomboom/>

Role models



Figure 6: Heather Matson is a public figure and 'small cottage' manufacturer and retailer of personalized ostomy covers

Maybe Astrid is a role model for other stoma patients in the way that she presents herself and shows that you do not have to hold back even though you have an ostomy. Other persons with an ostomy, who have gone public, also share their ideas when it comes to personalising the design of your ostomy. One of the designers that creates and sells different ostomy covers is Heather Matson from the US who, with no creative background, taught herself to sew (Figure 6). Under the title 'I design my own ostomy bag to feel sexy' she is represented on many video channels, explaining her story⁷.

Both Astrid and Heather share honest and reflective thoughts about how they deal with their conditions.

When recently interviewing Bendix (2018) to understand the difference in large industry versus smaller cottage industries in order to identify challenges in personalising wearable health design, he explained that Coloplast has a fifteen-meter long production machine (costing 1 million Danish Kroner per meter) to produce approximately 167 different styles of SenSura Mio. So adding this up with various sizes and colours would be a difficult and heavy multiplication of the production unit.

Workshop

To create a dialogue and critically reflect if an ostomy bag should be a fashion accessory a workshop was held. Four participated; Jakob Bendix, Nadia Ryding - a trained stoma nurse and shop owner of CPH Femme (a shop with a focus on fashion and lifestyle products for women diseased with cancer, stoma or those who are recovering to deal with a new every-day life) and Astrid, who also blogs about her daily struggles at CPH Femme's blog. They all participated alongside with the author.

⁷https://www.facebook.com/pg/stomapetunia/photos/?tab=album&album_id=150041322247833

The framing of the workshop was for the participants to create two different pouches that visualize their personality in a 'mild' and a 'wild' version.

Insights

Input from Astrid, Nadia and Jakob brought up relevant dilemmas due to a personalized design approach. Jakob was the one around the table who had most experience in designing ostomy bags, and due to this, he created a wild version, though still in grey. Nevertheless, his wild edition could be a complete revolutionary approach towards the design of the pouch, as an ostomy bag designed for the moving body, and thereby shaped very differently (Figure 7 A).



A)

B)

C)

D)

Figure 7: A) Jakob's wild version; B) Astrid's mild version, for comfort and support; C) Nadia's wild version, questioning situations where the pouch should not be discrete; D) The author's wild version of a bag that surrounds and completely covers the shape of the pouch.

Astrid's mild version, in a material that reminded her of her active life as a Judo sportswoman (Figures 5 and 7B), was created in a neat style. She decorated the pouch with two laces of silk band to make it comfortable and support her personality while wearing it. Nadia's wild version could work as a fashion accessory together with a bikini or for participants in a carnival, making a lively and festive expression. Her design, as well as Astrid and Jakob, related very much to the different situations ostomy wearers face in every-day life, and by that the personalized design approach is

relevant and arguable. Although, and by Figure 7D, the personalized design approach questions the existing product, to provoke an understanding of how an ostomy bag should look and be like.

In this sense, Jakob came up with some interesting feedback, saying what if we started from scratch to re-think the bag, also due to his 'wild' idea of a complete other form of a reservoir for the body waste.

A further step in the process could be to present the styles for non-wearers of ostomy products, to reflect emotions and thoughts when experiencing the different objects. Personal associations and sensory imaginations play's a huge role here, since we layer memories and connotations individually.

Concluding discussion

Designing in the area of taboo, stigma and discreteness, function is key. Inspired by fashion and textiles design, Coloplast creates products with even more appealing qualities than only function implies; involving the wearer's sense of self, changes in material and colour. One could ask if Coloplast's award winning re-design is that different from its former styles. Taking this a step further, the workshop raised new questions. Why should an ostomy bag be discrete? Could it be a personal choice and supplement to our every-day wardrobe and mood?

The intentions behind the SenSura Mio as a piece of accessory design are contrasted by the opinion of the wearers from the questionnaire. In the analysis almost 50 % of the participants did not link the design of SenSura Mio with their identity. Nor did they think that the SenSura Mio fitted their personal preferences or that the design was of importance to them. So, despite Coloplast's goal of designing and developing appealing products, almost 50 % of the wearers responded that what was of most importance to them was functionality and that the design of SenSura Mio had to fit all. This fact could be framed as a paradox in the personalization of wearable health design – to raise another question if wearable health design is for habitual use, should it be mass-customized to also fit personal needs? Just to say, that there is a need for more cottage industries, to deal with such challenges for the wearer.

If the pouch looks like a fashion accessory, rather than a wearable health device, could it then break down the taboo and stigma?

This leads to question if Coloplast succeeded with a personalized design approach in the design of SenSura Mio. At least they opened up ideas about implementing fashion and textile design, as a starting point relating to these industries. As the paradox concludes, it is a complicated task to produce 167 different everyday wearable health devices in different size, colours, texture and material to meet the individual needs of the wearers – which leads to discuss if an ostomy bag even can be seen as a fashion accessory?

The framing of the workshop opened up new perspectives of how wearable medical devices could be designed. There was no cost price, need for feasibility or production requirements for creating

personalized mild and wild versions of ostomy bags, for individual preferences. Thus, this approach facilitated a different environment for creativity and new ideas of how to develop and design such wearable health devices. This explorative and open-ended approach could be a contribution to scope personalized wearable health design as future fashion accessories for the individual.

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An Evaluation of the Accessory Approach in the Design of Personalized Wearable Health Devices Using a Biopsychosocial Framework

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ABSTRACT *Incorporating an accessory approach into current systematic approaches in health design enables a personal addition to worn health devices. This paper presents a research project between nine accessory design students and Sahva, the Danish body aids company. The project shows how accessory design skills, practices and methods can contribute to the development of personal wearable health devices, as current designs often ignore the psychosocial preferences of the wearer.*

The project was analysed using Bush's (2017) framework for wearability that provides a biopsychosocial model for understanding and defining the wearer's personal needs towards health devices. The findings from the analysis support the consideration of the accessory approach for wearable health devices; since this approach clearly includes a focus on these personalized preferences of wearability that the wearer experiences/holds towards wearable health devices. Such a design approach develops Sahva's existing perception of its clients by demonstrating ways to articulate the personal needs of the wearer and thereby create personalized wearable designs.

Keywords: Accessory Design; Wearable Health Devices; Accessory Approach; Biopsychosocial Framework

Introduction

This paper explores how accessory design can contribute to the design of personal wearable health devices; since current design approaches ignore the psychosocial preferences of the wearer by focusing on a biomedical model (Bush 2015; Bush and ten Hompel 2017).

Responding to the need for incorporating wearers' biopsychosocial needs in wearable health design processes, Peta Bush (2017) has developed the 8 Layers of Wearability model (fig. 1) to identify important design factors. The model is used to analyse how nine students use accessory design skills, practices and methods to affect their understanding and defining of the wearer's personal needs.

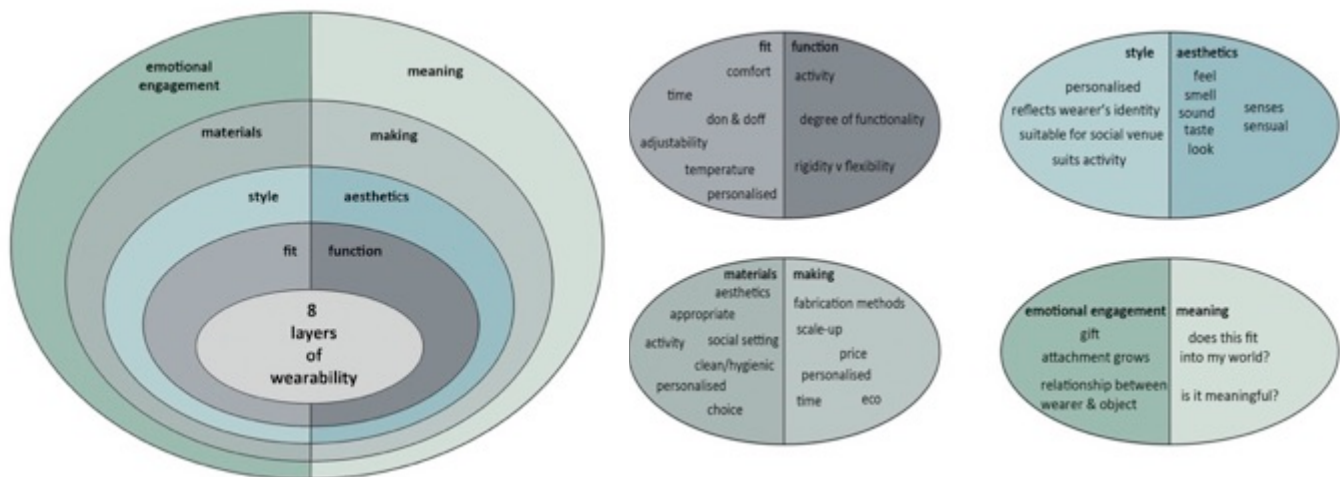


Figure.1: The 8 layers of wearability, according to Bush and ten Hompel 2017.

Bush's model identifies the following design factors: fit, function, style, aesthetics, materials, making, emotional engagement and meaning as affecting wearability, a term that describes how wearable an object is perceived to be by its wearer.

According to Ravnberg and Söderström (2017), personal tastes with regards to aesthetics are the main reason for the rejection of assistive technologies. Profita et al. (2016) state that the acceptance of assistive wearable devices is influenced by social factors such as poor aesthetics, gender/age appropriateness, social acceptability and concerns that wearable health technology is stigmatising (Phillips and Zhao 1993; Parette and Scherer 2009).

Exploring this, accessory design practices are of interest for medical wearables, as they activate personal preferences (Møller and Kettley 2017), i.e. biopsychosocial values of the wearer. Accessories are also objects that people wear close to the body, however, people's relationships to them are very different to that of wearable health devices. We need only to consider the wearer and their wedding ring, or favourite scarf to be aware of this developing relationship.

Therefore, we propose the broad category of accessory design, from jewellery to clothing accessories, where its design skills and practices concern both tangible and embodied understandings of identity, function, emotions, stories and materials, as well as those design practices that concerns small-scaled refined making processes, to support a particular framing for personalising wearable health devices. We frame this as the accessory approach (Møller 2018) to incorporate accessory design methods when designing wearable health devices.

Aim

To evaluate the accessory approach, a research project between Danish orthosis company Sahva and nine accessory design students was developed to explore the design of personal objects with four of Sahva's clients who consented to taking part (table. 1).

Table 1. The research project was framed as a five-week teaching programme.

Week 1	Week 2	Week 3	Week 4	Week 5
Literature review of accessory design	One-week workshop with Dr Jack Cunningham and Prof. Sarah Kettley	Second meeting with the Sahva clients	Two-day workshop with Peta Bush	Photo shoot
First meeting with Sahva clients	Two-day workshop with ten objects on a string + Three-day workshop of making a sensory jewellery piece	Lecture on 'Ethics in Design'	Introduction to person-centric wearables design and the '8 Layers of Wearability' model	Final presentation for Sahva. The nine accessory design students present their findings and work
Studio work		Studio work	Studio work	

Demonstrating how the accessory approach can contribute to the development of personal wearable health devices, Sarah Kettley, Jack Cunningham and Peta Bush were invited as facilitators in the research project due to their relation to accessory design as well as design research.

Methods

In week one Kettley introduced a method that Astfalck had (2011) developed in her *Mythemes/Lifelines*, and asked the students to create ten objects on a string that would best describe their Sahva client. Developing Kettley's brief, Cunningham then asked the students to create a sensory piece of jewellery for the individual wearer. In the fourth week, Peta Bush, who also focuses on the wearer's personal needs in her research into wearable orthosis design, facilitated a two-day workshop.

Analysis

Bush's own frustrating experience of wearing medical devices, and orthoses in particular⁸, led her to question the current approach of orthosis design. In her PhD research she explores wearers' experiences and knowledge of orthoses using co-design techniques to identify design factors affecting the wearer's acceptance of the orthoses. Her findings about wearability (fig. 1) then became the framework for analysing the nine students' work to characterise how and if they implement these eight important design factors. In table 2, we understand which factors drove the student's use of the accessory approach and how their different design projects and processes were perceived:

Table 2. To what degree the students incorporated important design factors for wearability.

Student/ Factors	Cornelia	Frederikke	Mondo	Tomoki	Amanda	Josephine	Anne	Aur�lie	Laura
Emotional Engagement	x	x	x	x	x	x	x	x	x
Meaning	x	x	x		x	x		x	x
Materials	x			x	x		x	x	x
Making				x	x			x	x
Style	x				x		x	x	x
Aesthetics		x	x		x	x	x	x	x
Fit	x							x	x
Function								x	x

Analysing the student projects using Bush's model leads to moments of astonishment (Alvesson and K rremann 2011; Brinkmann 2014). We use these moments to describe situations, experiences or actions regarding how the students can direct their design skills, practice and methods towards the Sahva client's personal preferences.

⁸ Bush has Ehlers-Danlos Syndrome, a connective tissue disorder and needs to wear medical devices to manage the condition

In the next section we use four of the above student projects to exemplify how the Sahva clients and the different workshops facilitated the student's outcomes.

Findings

One student, Frederikke, employs her accessory design skills, leading to a tangible and emotional description of how she perceives Per (her Sahva client) based on their first meeting. Kettley's exercise increased Frederikke's understanding of Per's story and identity. She used abstract symbols (fig. 2), e.g. the one solid ball of happiness, which she made in glittery paper and folded as a round cube, to describe his personality.



Figure 2: Frederikke and her tangible description of Per - her Sahva splint wearer, due to his stroke and a half-sided paralysis.

Furthermore, she used neoprene material together with metal to describe him as a person who likes functional objects and has a passion for heavy metal music. The light skin coloured pad she holds in her right hand is a symbol of Per's tattoo on the back of his knee, where he puts his electronic muscle stimulator. Per related to this immediately, when Frederikke presented the string at their next meeting. He was very touched by seeing how she had portrayed him, which facilitated a closer connection between them with rich and emotive dialogue.

The sharing of these ten objects was an astonishing moment, in that the activity facilitated a common third⁹. Therefore, this activity precipitated a very different conversation than their first;

⁹ A concept that uses an activity to strengthen the relationship between people, and to develop new skills for opening up an emotional conversation. (Thempra 2017).

now Per was able to be more open about stories (normally kept private), relating to his traumatic accident, and their effect upon him.

Frederikke's sense of translating these personal details into objects; her handling of difficult emotional narratives, as well as her small-scale refining process of the information, became a tangible tool for her to revisit during the design process. Also, the task enabled Frederikke to approach Per and his condition empathically and allowed her to fully address Per's biopsychosocial needs in her design solution.

Sensory approach



Another student Amanda, and Dorthe, (Sahva orthotist and prosthetic-leg wearer), shows another important element of the accessory approach, (fig. 3), where Dorthe wore a brooch designed by Amanda inspired by the string and Cunningham's sensory brief.

Fig. 3: Amanda created a brooch (based on the ten objects on a string), which Dorthe wore for two weeks, along with diary entries about her experience.

Dorthe was struck by how well this brooch embodied herself and her personal style; writing in the diary she remarked that it was incredible that Amanda could create this jewellery based on only one conversation. In this respect, Amanda's use of the methods increased her empathic understanding of Dorthe, resulting in a brooch that held both emotional and sensory meaning as Dorthe wore the brooch.

Use versus wear

Cornelia (student) worked with Christian, a prosthetic wearer. Although Cornelia experienced difficulties connecting with Christian, she continued her design process by investigating Sahva's materials (fig. 4 A). She compared these with products from her home, which she associated with use (fig. 4 B).



Fig. 4: A) Images from Cornelia presentation, and her exploration of Sahva products, which she relates to her own functional objects. B) The objects Cornelia relates with wear.

She argued that objects for use are made of cheap materials and used mainly for functional and practical reasons. Also, there is little detailing, and the materials are mainly grey, black and uniform colours. In Bush's workshop, the students were introduced to the difference between wear and use, and Cornelia used this understanding in an exploration of her worn objects. Here she found natural and precious materials, with small-scale details that characterise her personal style. This led her to create two sets of materials, based on her findings from the previous exploration (fig. 5 A), which she presented to a group of blindfolded persons, without informing them about her project (fig. 5 B).

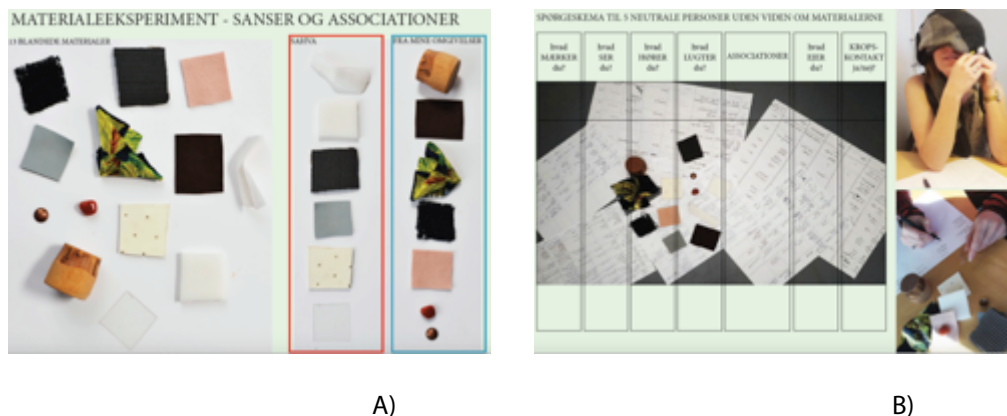


Fig. 5: A) Cornelia creates two material sample-sets, based on her observations from objects she wears and then materials used in Sahva's products. B) Afterwards she presents the materials to a group of blindfolded participants.

As they touched the materials, she asked them: 1. To explain what they associate with the materials. 2. If they would like to wear the material close to their body.

In this way Cornelia explores five important design factors (table 2) and identifies that the test participants rated the materials Sahva uses quite negatively, as they associated them with work

wear and other objects related to one-time use, such as baby napkins and packaging. In response to question 2, her participants were much more positive about the sample materials connected to wear. Thereby Cornelia identified issues related to the wearer's aesthetics and fit in terms of comfort, through a sensory experience of touching and associating the materials.

Accessory design skills

In the workshop with Bush, the students were also asked to develop quick prototypes to challenge existing perceptions of a Transcutaneous Electrical Nerve Stimulation (TENS) machine. Bush wears it on occasion to manage pain. According to Bush, the machine has many issues: the placement of buttons, ways of wearing, as well as the application of the pads to the body.

Aurélié chose to re-design the TENS machine as personalized jewellery, using nanotechnology, and natural, precious materials. (fig.6). Her re-design challenged the perception that wearable health devices have to be chunky, sporty or what the designers behind the TENS machine aimed for. Her concept was a neat and desirable solution that addresses fit and function. Further developments included a necklace with a rechargeable pendant for the pads that can be charged through body motion.

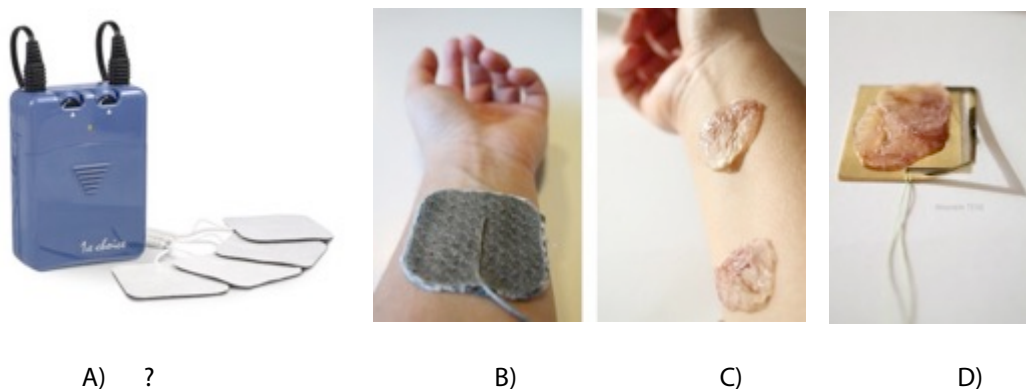


Figure 6: A) Bush's wearable TENS machine. B) Aurélié shows the existing pads in function. C) She then incorporates a natural element, flower leaves, to make the pads more beautiful. D) Aurélié embeds the pads on a wearable neckpiece that through advanced nanotechnology could function as another TENS machine.

The flower petal stylized pads could also be varied, along with the shape and style of the pendant, to meet the wearer's style and aesthetic preferences, and thereby become meaningful due to its personalization. In her treatment of the materials and the solutions, it seems that accessory design, and its focus on the emotional engagement between wearer and object, inspired her process of making to address all eight layers in Bush's model.

Discussion

How did Sahva react to the student's ideas and outcomes and the particular accessory design practice perspectives, skills and methods presented in this paper? Although Sahva raised relevant issues about regulations, time issues and budget, the students surprised the Sahva attendees with their different approaches towards personal wearable health design.

Dorthe (Sahva orthotist and prosthetic wearer), stated that the experience had made her reconsider her professional approach. At the final presentation, she explained that receiving the brooch from Amanda was like receiving a gift. This astonishing moment affected her thinking about her Sahva clients. She told that she had begun to develop a more holistic approach towards her practice, so that rather than focusing on biomedical needs, she also considered their personal information in order to design solutions that she could offer as gifts.

This particular notion made the Sahva attendees realise that the existing practice of treating their clients as users could be reconsidered to include the wearer's emotional and social perspectives. This was also recognized in Cornelia's project, which raised several issues for Sahva concerning their choice of materials. Her project demonstrated that use versus wear makes a difference for the touch experience of Sahva's products, as well as the sensory and emotional relationship between the wearer and the object. Sahva were really engaged with her findings and explained that although their existing approach is concerned with constraints and budget, cost restriction and procurement needs, the projects inspired them to think differently about their approach. Another argument could be made that more desirable and precious materials would make the prosthetics or orthoses be worn for longer, or even create a stronger emotional relationship between the wearers and the object, to affect economic issues related to sustainable perspectives and longevity.

In regard to new product development, the students' skills, practice and methods also inspired Sahva, particularly their existing perception of their clients. Frederikke demonstrated ways to articulate the personal needs of Per. Aurélie used her insights to create a ready-for-market product, a TENS machine, as long as there is proof-of-concept for the incorporation of the nanotechnology. Influenced by the accessory approach, she made a well-fitting, functional, stylish and aesthetic health device that greatly emphasized emotional engagement and meaning for the wearer. Thereby the different projects evaluated the need for a different approach towards wearable health devices. This could be the accessory approach.

Conclusion

With the help of Sarah Kettley, Jack Cunningham and Peta Bush, the accessory students created nine well-devised projects, to meet the personal needs of four Sahva wearers. By incorporating accessory design skills, practices and methods, the students transformed emotional information into tangible objects to address the Sahva wearer's personal needs. Using Bush's (2017) 8 layers of wearability attached further personalized design factors to challenge existing perceptions of assistive wearables design, alongside the accessory approach, to generate an empathic and holistic understanding of the wearer. Evaluating the student's use of accessory design skills,

practice and methods, the accessory approach facilitates wearable health designs for the wearer, to be carried on the wearer's body and to be about the wearer. This frames a personal need of the wearer on physical, psychological as well as social levels.

Acknowledgements

The authors would like to thank Sahva for the opportunity to engage the amazing accessory design students; Amanda Brøndum List, Anne Voight Sonnichsen, Josephine Graff Vallant, Frederikke Ryhl Toft, Aurélie Varga, Tomoki Hirano, Chieh Ao aka Mondo, Laura Knowles and Cornelia Therkelsen. Also big thanks to Jack Cunningham, Sarah Kettley and Peta Bush for being such great inspirations and for sharing and discussing your work and approaches. Lastly, this project could not have happened without the help and personal contribution of Christian, Dorthe, Per and Helle. Thank You!

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Bringing behaviour change and design together through co-development of an app for improved bladder control in young people.

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ABSTRACT ONLY *Technology that delivers support for young people to self-manage daytime urinary incontinence (DUI) is required. DUI often does not resolve with age, and severe incontinence often persists into adolescence (Maternik et al. 2015). First line treatment is urotherapy – retraining the bladder through behavioural modification by establishing regular toileting habits and drinking (Mulders et al 2011). Adherence to the timed schedule is critical, but is a demanding task for young people, depending heavily on factors such as maturation, self motivation, assertiveness, and support from clinicians. Consequently, many struggle to adhere to urotherapy and are prescribed supportive medication.*

This project sought to co-design with young people an app to support adherence to Urotherapy. The development team included app developers, health psychologists, design and usability specialists. The intention was to combine behaviour change and design approaches in the development of an app based self-management intervention. It was recognized that a combined approach was required to ensure an effective and accepted solution that encouraged healthy behaviours.

Three participatory design workshop were co-facilitated by Health Psychologists alongside Design specialists. A range of co-creation activities were used including mapping a typical day, sketching, graffiti walls, and card sorting (Fig 1). An additional workshop with a young people's research group from the children's continence charity ERIC was also undertaken, and regular feedback sought from national expert clinicians (Paediatric Continence Forum).

The workshops enabled identification of specific user requirements, defined the behaviour changes required by Urotherapy, and identified processes/beliefs that influence these behaviours (workshop 1); identified optimal ways of delivering behaviour change techniques via the app and explored visual representations (workshop 2), and tested the usability of the app (workshop 3). The results, as well as identifying specific user requirements in this domain, have informed the creation of a prototype smartphone application (fig 2).

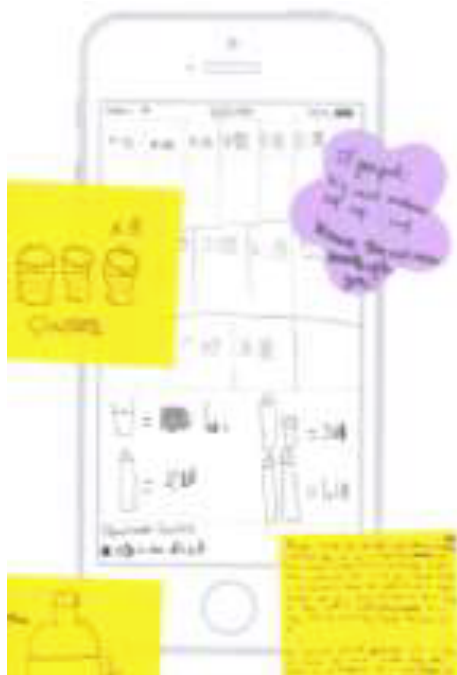


Fig1. Example workshop output

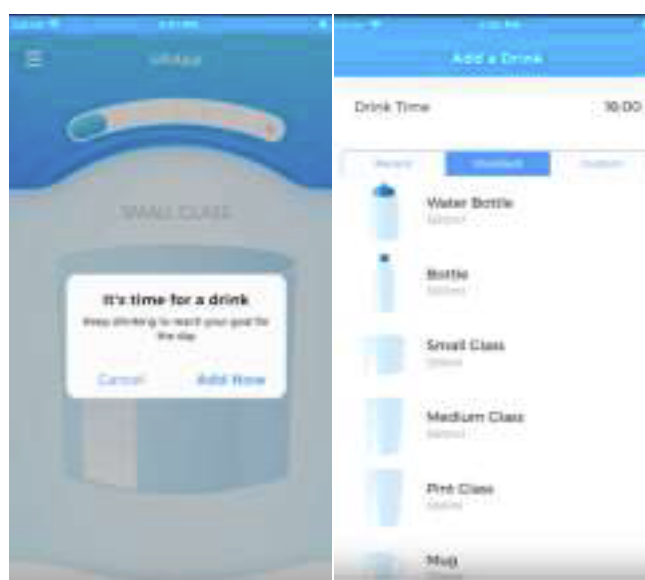


Fig2. Example app screenshots developed

Co-development of an ethical framework to guide design research in a living lab focused on living well for longer

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ABSTRACT ONLY *Living Labs (LLs) are a mechanism for bringing stakeholders together to co-design and cocreate novel content for innovative products, services and practices. Recognized at European level since 2006, in 2018 the European Network of Living Labs (ENoLL) counts over 433 members worldwide, 430 in Europe. However, researchers highlight the still diverse usage in the literature of the LL concept and claim the need to have a convergent theoretical (and methodological) framework. Further, it is argued that LL initiatives lack formalised ethical guidelines for the design, development, and implementation of research and development projects. This paper will explore the challenges of developing a LL environment to enable design for improved health and wellbeing, especially when involving older adults who may have reducing cognitive and physical capacity. Our particular focus is on ethical conduct and research participation.*

Using interviews and co-creation workshops, the views and requirements of 56 stakeholders were explored. A qualitative research strategy was used to (1) investigate the experiences, views and concerns of researchers in this context as well as residents, family members and staff of two living environments engaged in LL research; and to (2) co- create an ethical framework that can guide the design and implementation of projects involving in particular, older adult participants.

The results identified researcher experiences of developing and delivering research in a LL setting, and identified the related challenges and concerns. As a result, solutions are advanced as well as a pathway to developing future LL projects. It is concluded that research in LLs should rely on a holistic ethical framework and supporting toolkit to guide multi-stakeholder collaboration and knowledge sharing in such research and development initiatives.

Keywords: Co-creation; design research; ethical frameworks

ACCESS ME NOT – an animation to communicate research results to a health care provider

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ABSTRACT *Access Health and Community is a local health care provider in the Metropolitan area of Melbourne (Australia) and approached Swinburne University's Living Lab to redesign their waiting room. The aim of this project was to reinforce the reputation of Access Health and Community as an innovative service provider for the community. Our research indicated that achieving this goal was not only a question of an interior design solution as originally requested, but also to allow patients to access multiple services. The research framing this animation focusses on patients and staff emotions – in particular, how they feel and how would like to feel in the waiting room. To communicate to the client the richness of the data and the emotions associated with the current service barriers an animation called 'ACCESS ME NOT' was created coupled with an extensive report. It was the animation in particular that enabled Access Health and Community staff to understand the complexity of the data and the emotions of their clients. The animation has been used as a tool to communicate the service barriers to staff (for training purposes) and the Access Health and Community Board (for decision making). The Chief Executive Officer (CEO) reported on the use of the animation in the following manner:*

'I really did not have the time to read a one-hundred-page report - this animation is short, but it still tackles the same problems – the wide range of patients with complex problems. I could understand how the patients feel. I have never seen something like it. I showed it to the board [...] and staff and we had a laugh.'

The animation led to a new project to create a whole series of animations 'the Access Family' building on the existing characters to introduce the main services of Access Health and Community and reinforce their new branding.

Keywords: health media, animations, community health care, design communication

Background and Aim

The animation was developed using data collected in a co-design process with staff of Access Health and Community. All methods focussed on how staff would like their patients to feel as part of their service offering. Participants across five different organizational groups at Access Health and Community were involved in the data collection. They were 1) the drug and alcohol team, 2) the reception staff, 3) upper management, 4) occupational therapy and 5) health promotion.

The methods captured important user-centric narratives of current practice. A photo-documentation kit was used to explore service barriers, patient services and future directions, while a focus group elicited refined emotions to develop spatial design and service design recommendations (for details refer to Keirnan et al. 2018).

In order to communicate the richness of the data – the context, the perspective of the patients and their emotions facing service barriers—an animation was created. It was anticipated that this animation could be used to communicate to a range of stakeholder groups: the participating staff, other staff not directly involved in the project, and the management teams. The aim was for the viewers to empathize with the animated patients to better understand our suggested requirements for the waiting room concept.

Animations and Scenarios to Communicate Emotional Needs

Ramos et al. (2005) discuss cases where functionalities or complete systems were abandoned because they were not aligned with the feelings of their intended users. These authors focus on traditional business systems, but we suggest emotions are just as relevant in health environments. Proynova et al. (2011) argue that in health care information systems, stakeholders' personal values should be taken into account as they may uncover hidden requirements. Sutcliffe and Sawyer (2013) explore how motivations, values and emotions can hinder the achievement of system goals and Miller et al. (2014) treat emotional goals in software engineering processes as high level requirements for guidance.

Animations bring characters to life (Parent et al. 2009). According to Murdoch (2016) the mechanics of a story will determine, whether an audience member is engaged with an animated character and how they will feel about the character and their story. Thus, having the ability to explicitly identify an animated character's emotional state is an important part of the character's animation production. In our case if we are able to communicate the current negative emotions in accessing the health services we will be able to translate these into emotional goals as a future desired state and why this is necessary. Murdoch (2016) suggests when conveying character emotions in animations,

[...] 'it has great potential to be expanded across other mediums and processes where the emotional state of internal and/or external entities require visualization' (13).

To translate our data and emotions of patients into animated visualizations we use personas and scenarios as bridging mechanism as they can be used to explore the diversity of people's background, emotions and motivations, and how they would react emotionally to design decisions (Lopez-Lorca et al. 2014).

Carroll (1997) states scenarios describe the future use of design solutions, making them easier to design:

'The defining property of a scenario is that it projects a concrete description of activity that the user engages in when performing a specific task, a description sufficiently detailed so that design implications can be inferred and reasoned about' (1).

The scenario follows the basic structure of a story and typically contains similar elements such as actors, events, and goals. Stories enable readers to empathize with the people in the situation, which leads to questions about motivations, intentions, reactions and satisfaction. It is for this reason that we believe that scenarios are powerful when suggesting a new design of the waiting room that future patients must engage with emotionally.

According to Carroll (2000), emotions are not a 'nice to have' component of a scenario, but 'a condition of comprehension'. In this sense, the interpretation of scenarios should include emotions to increase the understanding of the user and his/her use activities. However, the emotions felt by a specific user will differ widely based on their context, such as cultural background, gender, age, belief systems, and living situations. As such, emotions should not be tied to scenarios, but Personas acting in those scenarios.

Personas are often used in combination with scenarios, because of the close connection between personas and the broader scenarios in which they are embedded. Pruitt and Grudin (2003) state that scenarios themselves are only effective when used with personas, and they 'provide a conduit for conveying a broad range of qualitative and quantitative data'.

Our observations are aligned with former research from one of the authors (2004), which compared textual scenarios with visual scenarios, and observed that emotional aspects can form a powerful connector between the visualized scenario and the reader. Emotional aspects help to provide and understand context, which cannot be achieved by simply verbalizing the emotions of the user.

Animation Process

Study Data as Basis for the Scenario

Here, we present one of the use case scenarios (three were created in total) with an emphasis on the problems and barriers faced by patients. The scenarios visually present the data collected from the primary research methods as storyboards. While they are not one single user narrative, the

storyboards' purpose is to illustrate a collection of user insights discovered during the primary research phase. The scenarios are centred around patient and staff experiences, namely concerning spatial, service and technology-oriented offerings:

Patients in wheelchairs may require using one of the limited parking spaces for people with disabilities. When patients were aware of these spaces despite poor signage, it was noted that moving towards the entry of the building the Kent Street hill is difficult to ascend using a wheelchair or other assistive devices (storyboard panel 1).

There is a lack of height sensors to detect movement at a certain height causing patients using wheelchairs being ignored by the doors (storyboard panel 2).

When a patient enters Access Health and Community, the height of the reception desk excludes people in wheelchairs. The data shows that patients who use wheelchairs are not able to discuss with the reception staff details about their appointment and health records (storyboard panel 3).

Many patients using wheelchairs need to wait in the children's play area for easy access to treatment rooms, and hence are cutting off access to the play area for children (storyboard panel 4).

In many instances, patients and staff have expressed concerns about narrow hallways that only accommodate a single pathway from the waiting area to GP suites not allowing people who are using prams, walkers or wheelchairs to use the narrow hall simultaneously (storyboard panel 5).

Storyboard Creation

The scenario 'Access me not' focusses on Joan's story, and her difficulty and anxiety using the waiting room space at Access Health and Community.

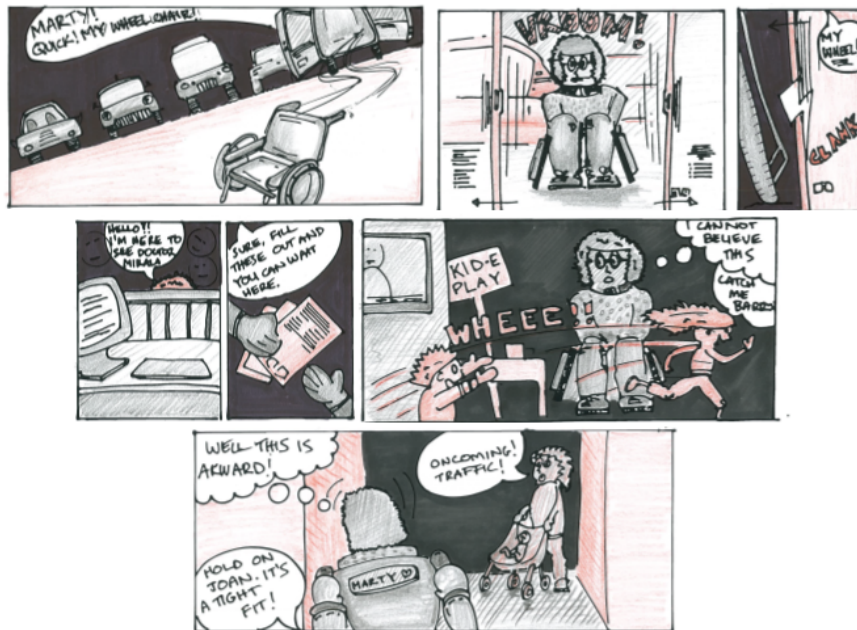


Figure 1: Storyboard Panels 1-5 (excerpt from original scenario).

Visual design language and asset creation

Context creation: For staff to identify with the animation and its content the presentation of the environment was crucial. The iconic building asset (Figure 2) was such an important asset that it was requested that in future animations all clinic locations need to be visualized.

The characters (Figure 3): They are key in transporting the message. While the information is to a large extent negative, the friendliness of the characters helped Access Health and Community to take the patient view on board. They also particularly liked that the colours support the new brand image. Importantly for us as researchers they are a way to create Personas in an anonymized way without having to settle on a real person.

Voice over: In conjunction with the characters the voice was friendly and emphasis was put on a local accent (Australian voice).

The script: To wholly emerge the script was set up as a dialogue. This helped to understand the situation. As this deliverable was not part of our agreement we were not sure how our collaboration partner would take the play on their name in the title 'Access me not'. However, it was received as intended and seen in a humorous way.



Figure 2: Provider building – the former post office.

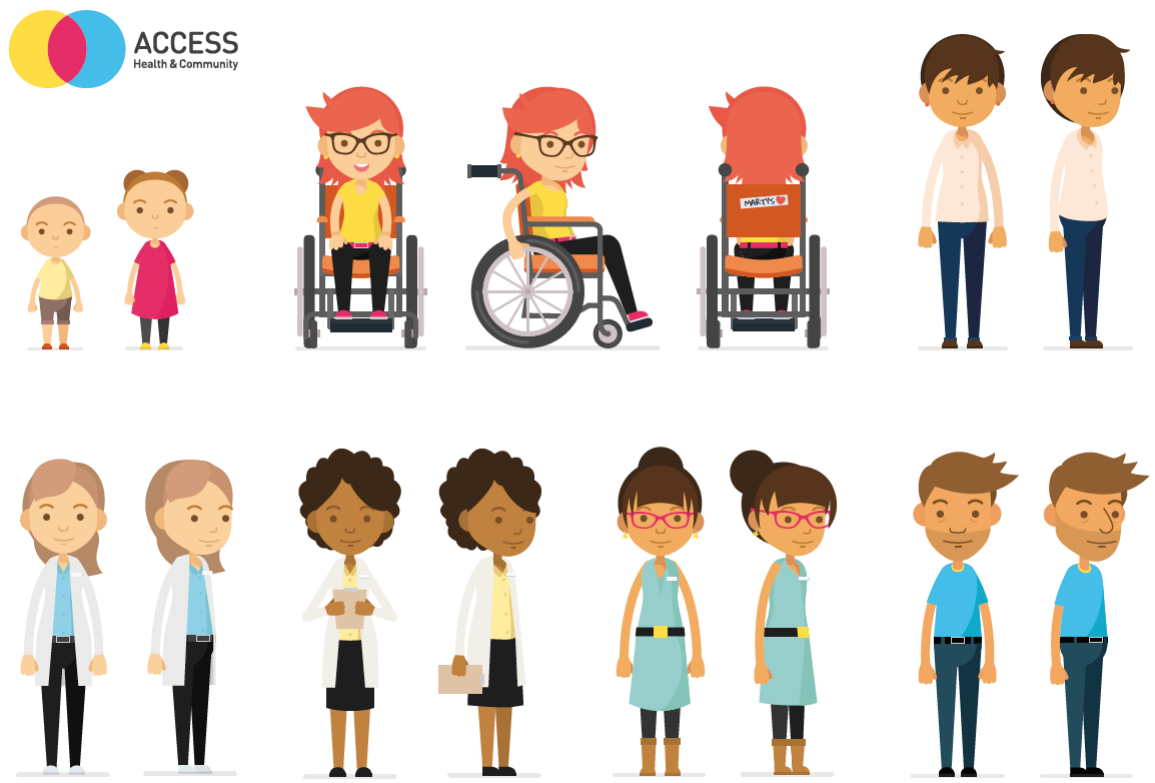


Figure 3: Character development.

The final animation

The final animation (figure4) can be accessed at:

<https://vimeo.com/257605303/8695065691>



Figure 4: Frames from the final animation matching storyboard panels.

Concluding Comments

This animation has not undergone a formal evaluation process. However, the CEO commented on the success of the animation (quote in abstract) and it's use for training of staff and used in a board meeting for convincing people of the need of making changes of the waiting room which will be redesigned according to the outcomes of this research (see Keirnan et al. 2018). A whole follow up project was set up to create animations as innovative health media. Finally this animation received a Honorary mention in the International Design Awards (IDA).

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Antimicrobial Stewardship in Asymptomatic Bacteriuria: Co-creating to promote appropriate care

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ABSTRACT *Inappropriate use of antimicrobials to treat asymptomatic bacteriuria is an issue across health care. Overutilization of urine testing, and treatment of positive urine test results regardless of patient symptoms is common. This is an inappropriate use of resources with a potential for harm, including the development of bacterial resistance, adverse reactions to antibiotics and Clostridium difficile infection. The Appropriateness of Care: Asymptomatic Bacteriuria project partnered with the Physician Learning Program at the University of Alberta to identify physicians and nurses' beliefs about urine testing for infection, the processes they followed for "routine" ordering of urine tests, and their opinions about the core message of a suite of clinical decision making and communication tools. To achieve this, we developed three co-creation workshops. The co-creation workshops helped to ensure the core messages were appropriate to the users. They were also a learning experience for healthcare providers. We propose that co-creation might be an effective methodology for the translation of knowledge in healthcare settings.*

Keywords: urinary tract infections, asymptomatic bacteriuria, human-centred design, co-design, knowledge translation.

Introduction

Inappropriate use of antimicrobials for the treatment of asymptomatic bacteriuria (ASB) is a commonly recognized issue across health care (American College of Radiology 2012; Barlam et al. 2016; Fleming-Dutra et al. 2016). Overutilization of urine testing (both urinalysis and urine cultures) as routine tests or tests of nonspecific symptoms, combined with treatment of positive urine test results rather than assessing results in the context of patient symptoms is common practice recognized by clinicians as inappropriate use of resources (PasayET AL. 2015). Root causes of this problem include:

- Belief that non-specific status changes or cloudy/foul-smelling urine (particularly in the elderly or catheterized) are the result of UTI (RoweET AL. 2014).
- Belief that positive urinalysis or positive urine cultures are always indicative of UTI (Juthani-Mehta, 2015).
- ‘Routine’ ordering of urinalysis and urine cultures as part of a panel of investigations, is accepted practice in many scenarios in healthcare (Rowe et al. 2014).

This can result in potential harms of unnecessary antibiotic therapy, including the development of bacterial resistance, adverse and allergic reactions, and promotion of *Clostridium difficile* infection (File at al. 2014).

The Antimicrobial Stewardship in Asymptomatic Bacteriuria (ASAB) initiative is designed to collate best practices from across North America and integrate findings and lessons learned from Alberta initiatives to deliver a province-wide, transdisciplinary set of interventions to improve utilization of urine cultures and reduce inappropriate antibiotic treatment of ASAB.

ASAB partnered with the Physician Learning Program at the University of Alberta to identify physicians and nurses’ beliefs about urine testing, the processes they follow for “routine” urine testing, and their opinions about the core message of a suite of clinical decision making and communication tools. To achieve this, we applied a human-centred design approach, sometimes called design research (Breslin, Mullan, and Montori 2008; WittemanET AL. 2015). Human-centred design is known as a participatory approach that prioritizes users’ needs and collaboration (Bate and Robert 2007; Roberts et al. 2016). The approach has been shown to increase the usability of tools in healthcare (Garvelin et al. 2016). Co-designing, one of the methods used in design, has been embraced in healthcare as an effective way to involve the users in the planning of actions and tools (Bate and Robert 2007; Donetto et al. 2015). The approach embraces collective capacity to iteratively understand a problem and prototype possible solutions with the people that will be using them (Sanders and Stappers 2008). For this project we developed three co-creation workshops. For space reasons, in this paper we will focus on one of the tools: an algorithm to facilitate when to order urine tests.

Methods

We used a human-centred design approach, known in healthcare for its effectiveness in incorporating the users in the design process (Witteaman et al. 2015). Three activities were developed during the co-creation sessions: process mapping, co-analysis of the existing tools, and generation of ideas. The co-creation sessions were facilitated by a physician, specialized in infectious diseases and a human-centred designer. The facilitators introduced the problem at the beginning of the workshop from a medical and a design perspective.

To foster access to the latest research findings on asymptomatic bacteriuria, we placed 15 large quotes on the wall from the article ‘“Urinary Tract Infection”—requiem for a Heavyweight’ (Finucane 2017) and invited the participants to walk and read them. The goal was also to motivate and promote interest in the subject.

The first activity was to co-create a process map, which lasted 10 minutes. The goal was to identify the decision-making process participants follow in the emergency department (ER) and acute care when assessing urinary tract infections (UTI) and (ASB). Participants reflected on the process, to become aware about their practices.

Groups then took 10 minutes to discuss the process map with other participants. During the discussion, each group described the different steps to the other.

To facilitate the activity we used dialogue prompts, which are tools that create a communicational space (Frascara 2016), a space for interaction, reflection and generation of ideas. The pre-structured activities developed depending on the problem explored (Figure 1).



Figure 1. The dialogue prompter used to foster dialogue during the co-creation.

The second activity aimed at collaboratively analyzing the existing tool and at generating ideas that will respond to the participants' needs. A dialogue prompter (Figure 2) with pre-structured questions helped participants reflect on the sequence of information, the relevance and clarity of the content, the appropriateness of the vocabulary and tone of voice. Each group had 20 minutes to co-create the algorithm and 10 minutes to present their feedback to the other group.

Co-designing the UTI algorithm

Creating a UTI tool that will help you decide when and how to proceed

Instructions

Please look and read the UTI Acute care algorithm. Read and answer the questions below. Think about your reading situation when being at work. Write, re-write, add, delete or draw what would you change for the tool to fulfil your needs and wants.

- Are the steps and sequence in the algorithm clear?
- Is the content relevant to practise?
- Is it clear what to do?
- Is the vocabulary appropriate?
- Is it easy to follow the argument?
- Does the tone of voice match your expectations?

Primary Trust Algorithm for ASB - NURSING TOOL

Check if your patient is a **primary trust**.

UTI Symptoms

UTI Symptoms with Indwelling Urinary Catheter

Request urinalysis and urine culture

Presence of additional signs

Patient history / symptoms

Indications for urine testing

Send urine

Do NOT send urine

Empiric therapy

Start with the patient.

Are the title and subtitles helping you to navigate the tool? What would you change?

Are the chunks of information helpful?

Are the colour areas helpful?

Anything else you would like to change?

Figure 2.

During the first workshop verbatim notes were taken. The comments that the participants wrote on the tools were aggregated to the notes. Three team members participated in the coding and labelling session. The data was analyzed through a process of affinity diagramming to identify

themes and insights (Hartson, Rex, and Pardha 2012). Verbatim statements were written up on post-it notes and grouped based on their affinity. The affinity shows the scope of the users' problems and helps develop the design requirements of the tools (Beyer and Holzblatt 2017).

These findings were used to develop performance requirements to guide the design decisions. This is a process of transforming research findings; from what people do, why they do it, what they want and need, to what a design should do to satisfy the users.

Results

Participants

Forty-four people participated in three co-creation sessions. Participants were nurse practitioners, nurse educators, a nurse student, pharmacists, physicians from the Emergency, Gastroenterology and Orthopedic Departments at the University of Alberta Hospital.

In the first workshop we had six participants grouped in two tables, and in the second we had eight participants in two tables. In the third co-creation we had 30 participants, with a team of nurses: Unit managers, clinical nurse educators, staff nurses, licenses practical nurses and patient care managers.

The maps revealed a variation in the assessment and management of UTI and ASB. Participants indicated the need for a standardized practice. This confirms the need for the algorithm.

The main barrier identified for appropriate assessment was the time to receive the results, particularly in the ER (in emergency, time is an indicator of quality). Other barriers were related to:

- Coordination, it is difficult to follow up once the patient is moved to a different unit.
- Lack of information about the reason to order urine testing.
- Delirium as a symptom of UTI is an area of contention. Physicians are afraid of "missing something".
- Lack of information about the nature of urinary catheters. Indication, is the catheter new, intermittent, or chronic?
- Difficulties obtaining a quality urine sample.

The two main areas for improvement identified were education about ASB and that cloudy or smelly urine are not indicative of UTI. Other areas for improvement were:

- Education about best practices for urinary catheters
- To provide patient care units with data about on urine testing and UTI treatment
- To prompt providers to look for other potential causes of delirium (using protocols)

- To improve the process, making sure results follow the patient
- To change the urine test requisition to include the reason for testing

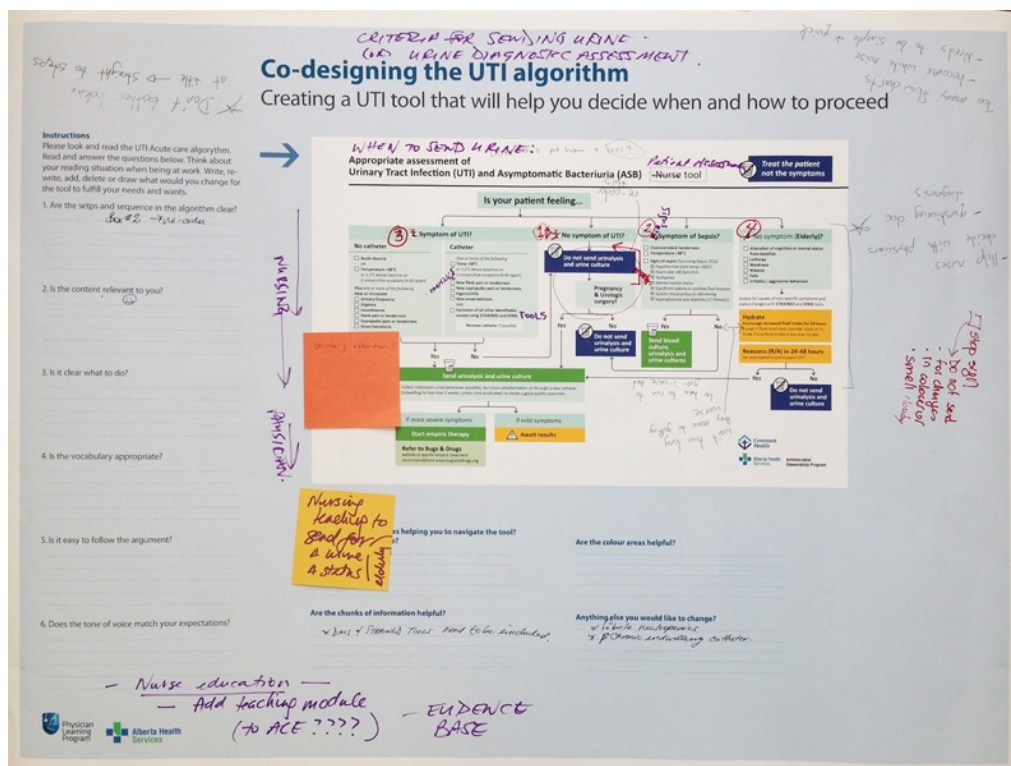
Based on our observations, it would seem that most part of the reflection happened during the discussion time, and most of the awareness during the mapping.

The dialogue prompter with the provotype helped to foster the co-analysis of the exiting algorithm and to identify possible ways to convey the information. Participants identified that the algorithm needed to clearly communicate who is the audience. They also expressed the need to communicate the fact that the algorithm is evidence-based in the title.

Participants identified that the algorithm contained two types of information: to guide decision-making and to educate. The algorithm was changed to focus only on decision-making.

Participants indicated that not all of the algorithm's boxes guided them, presenting some unresolved situations. Participants identified that introducing unknown tools in the algorithm document may be problematic and present some resistance to adoption.

Participants split the algorithm into two main groups: patients presenting with UTI symptoms, patients presenting with no UTI symptoms. As cloudy or smelly urine is not indicative of UTI, participants suggested to include a box containing this information in the algorithm. This helped developed a first prototype (Figures 3 & 4).



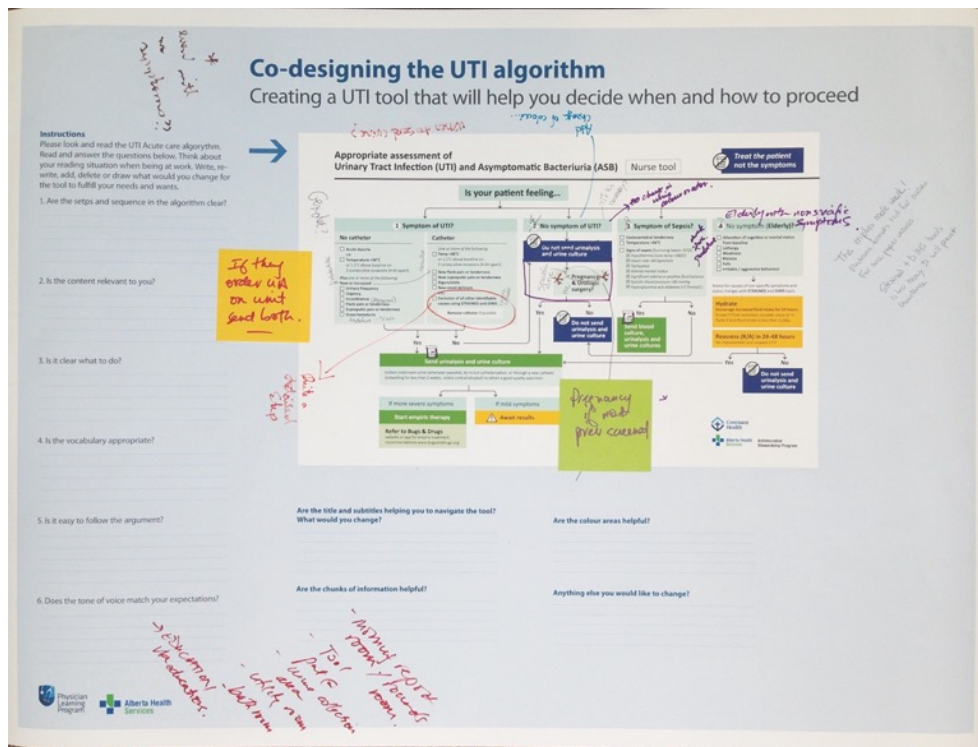


Figure 3 & 4. The algorithm co-created by the participants in Figure 2, helped co-design this prototype and start an iterative process

Discussion

We learned that healthcare providers are not always familiar with the current evidence on ASB. We also learned that healthcare providers are not aware that there is overutilization of urine testing. The Exchange Concept (Lefebvre 2013) proposes that for adoption to happen users need to be aware that there is a problem, and then offer a solution (the algorithm). The lack of awareness about urine testing overutilization might affect the adoption of the algorithm. Particularly, the fact that cloudy or smelly urine is not indicative of UTI was a point of discussion among participants. When reading the large quotes on the wall a nurse said: "This is not true." During the discussion another nurse mentioned: "This is not what I was taught in school." And while we were doing the co-analysis a participant expressed: "I don't even know how to pronounce asymptomatic bacteriuria."

The part of the algorithm relating to the elderly population required further work, to address participants fears of missing diagnosis of sepsis (a life-threatening condition caused by infection). It became apparent that the problem is not to design an algorithm, but to show that the process we are proposing will provide safer outcomes. As Collins (2018) explained “when humans are given a choice between their own judgment and that of a demonstrably superior algorithm, they will generally choose the former.”

The area related to patients with urinary catheters was problematic given the lack of information about catheters. Participants were aware that catheters need to be changed regularly (Gould et al. 2009; Soong et al. 2016), however nurses reported the lack of an easy and quick way to confirm when the catheter was inserted. This would require some system changes that are beyond the scope of this project. Figure 5 shows the final prototype.

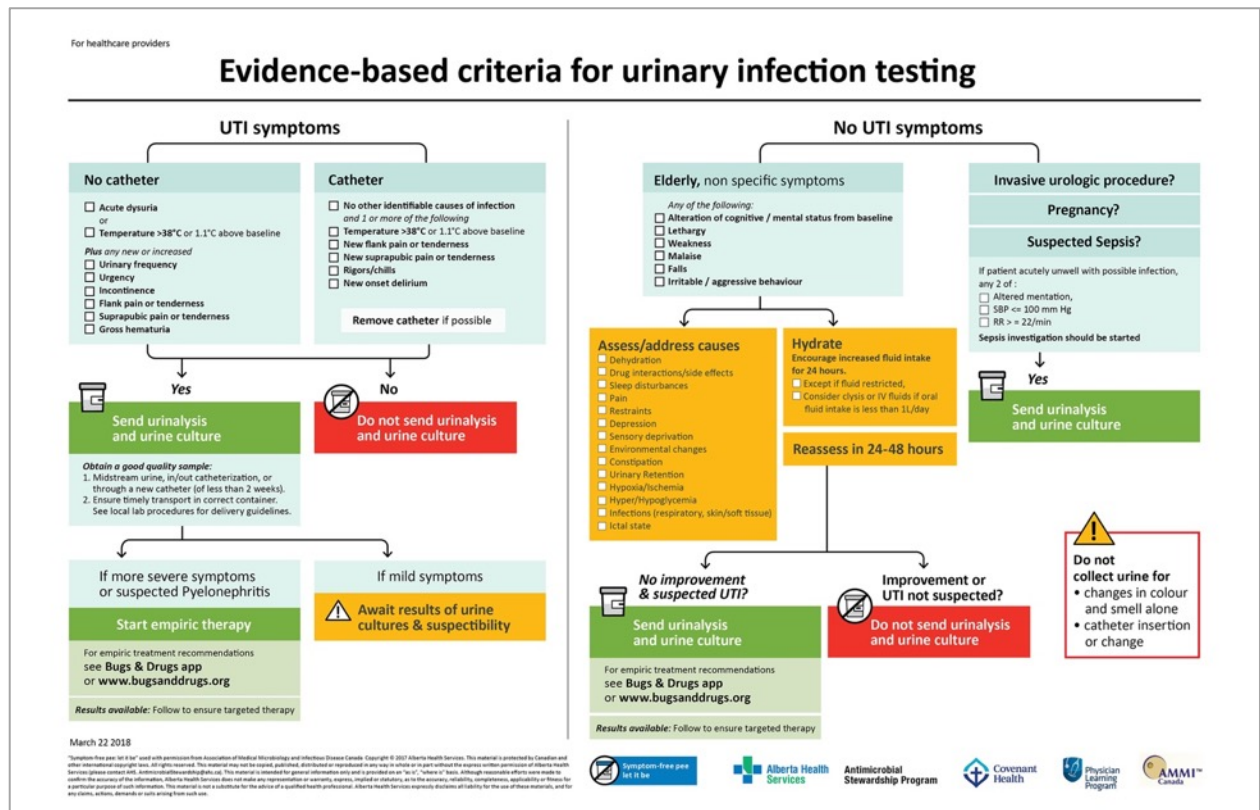


Figure 5.

There was an unexpected result. In the process of co-creating, participants become aware of the latest UTI evidence through conversing and co-designing the tool. In the last co-creation with 30 nurse participants expressed that this methodology was “a great way to answer questions,” “a nice way of learning,” “a place to address knowledge gaps,” and “an activity to foster critical thinking by having a conversation.” The conversation and making activity were unexpectedly an effective way of transferring knowledge (Greenhalgh 2017).

Conclusion

The co-creation workshops helped to ensure the algorithm responded to the healthcare providers and ASAB team needs, wants and expectations. Most importantly, the co-creations were a learning experience for healthcare providers. If the right team was present, knowledge gaps about asymptomatic bacteriuria were identified and immediately filled. Through the co-creation

workshop the team gained awareness about the issue and was ready to start implementing change. This aligns with the idea that adoption requires interpersonal contact (Greenhalgh et al. 2004).

The methodological model described here, seems to have been valuable to help establish a climate for research dissemination and use.

The method of co-creation might be an effective knowledge translation tool helping to foster “a dynamic and iterative process that includes synthesis, dissemination, exchange... of knowledge to ... provide more effective health products, and strengthen the health-care system” (Canadian Institute of Health Research).

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Creating caring conversations for patients living with obesity. The 5As Team program.

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ABSTRACT People living with obesity suffer from multiple health conditions, including diabetes and mental health. Managing obesity is affected by misinformation about its complexity and chronicity, resulting in unrealistic expectations by healthcare providers and patients. Effective obesity management has to be individually tailored for each patient. The objective of this project was to improve four communication tools by co-designing it with patients. A co-design approach was used to improve the efficacy and applicability of the tools through a working collaboration between patients, care providers, and researchers. The adoption of human-centred design can help patients and physicians to collaboratively design better healthcare approaches. We hope this study provides a valuable model.

Keywords: obesity, weight management conversations, human-centred design, shared-decision making.

Introduction

Patients with obesity frequently suffer from other chronic conditions, like diabetes or osteoarthritis. Obesity management in primary care requires an assessment of root causes (Sharma and Padwal 2010); including the *mental* (anxiety, depression), *physical* (musculoskeletal disorders, hypertension) and *social health* (occupation, relationships) (Sharma 2010; Loeb et al. 2015). Obesity management is challenging due to the medical complexity of patients, the socio-economic factors affecting their health, and the need to understand the connection between all these aspects (Kushner 2012; Peek 2009).

Obesity management demands personalised care planning to provide support tailored to the uniqueness of each patient. In personalised care patients and clinicians collaboratively identify, discuss, and decide actions for managing obesity. Personalised care planning is a conversation, or series of them, for managing the patient's health problems. This shared process is usually called shared-decision making.

Shared-decision making (SDM) tools help clinicians and patients engage in deep, unique, and valuable conversations (Stiggelbout 2012). The 5As research team created a toolkit to support obesity conversations (reported in Osunlana et al. 2015). Four SDM tools from this toolkit were selected for improvement. These are: the bubbles, the timeline, the 4Ms, and the goal-sheet (Figure 1).

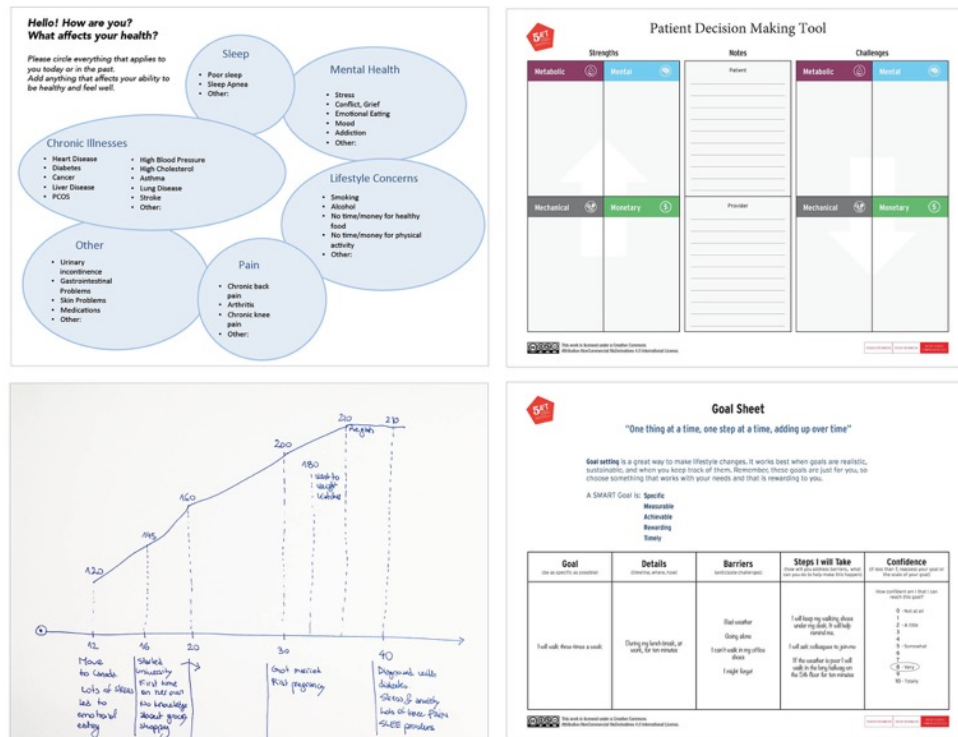


Figure 1. Above left, the bubbles tool; below left, the timeline; above right, the 4Ms; and below right, the goal-sheet.

Methods

Human-centred design: An approach to achieve Patient-centred care

Medical practice calls for the adoption of patient-centred care approaches. Human-centred design is often used in the design of SDM tools to address patient-centred care (Breslin et al. 2008; Bohemer et al. 2016; Witteman et al. 2015). Designing for people and caring for people both require a deep knowledge of and collaboration with 'people'.

The 5As Team understands human-centred design an approach where teams collaborate with patients. Human-centred design is a principle, not a method (Fascara 2017). In healthcare, we use human-centred design because people matter (Hargraves 2018), and hence we create knowledge collaboratively (Greenhalgh et al. 2016). We used co-design, a process of engagement, participation and collaboration to improve the four SDM tools. The bubbles helped identify current and past health issues; the timeline to discover life events that affected health and weight; the 4Ms to assess weight management considering Mechanical, Mental, Metabolic, and Monetary aspects; and the goal-sheet to set goals.

Participants

Patients were older than 18 years, spoke English, had different age, gender and socio-economic backgrounds. Most providers were from the 5AsT primary care teams (dietitians, family physicians, and mental health workers). All participants have used the tools.

The University of Alberta Ethics Board approved the study. The process was divided in 3 phases: 1) understanding the design problem, 2) co-designing the tools, and 3) observing performance. Observing is not reported here. Table 1 shows the structure of the study.

Study design

Table 1 study structure

	Previous work <i>Reported in Luig et al. in press</i>	Phase 1: Understanding the design problem	Phase 2: Co-designing the tools			Phase 3: Observing performance
Methods	<i>Observation, interviews, journals</i>	Observation	Co-design workshop 1 1hr 30 min 3 personas based on the observations	Co-design workshop 2 1hr 30 min 3 personas Role-playing	Co-design workshop 3 1hr 30 min 3 personas Role-playing	Done, but NOT reported here
Data collection tools	<i>20 videos of patients and providers using the original 4 tools selected for improvement</i>	9 video recordings of patients and providers using the original 4 tools selected for improvement	2 dialogue prompters 2 provotypes Verbatim notes	2 dialogue prompters 4 prototypes Verbatim notes	2 dialogue prompters 4 prototypes Verbatim notes	
Goals	<i>To investigate provider-patient conversations about obesity</i>	To identify the structure and nature of the conversations,	To collaboratively analyze and explore how the current	To understand the degree to which the 1 st	To understand the degree to which the 2 st	

	<i>and their effects on everyday life.</i>	and the tools' context of use.	tools help patient and physician.	prototypes work. To jointly envision how to improve them	prototypes work. To jointly envision how to improve them
Participants		9 patients 2 providers	3 patients 1 designer	5 patients 5 providers 1 designer	5 patients 5 providers 1 designer
Output			4 prototypes based on 24 performance requirements	Second 4 prototypes	Third 4 prototypes

The question to explore was: *How can we arrive at a patient-clinician interaction that offers conversation, not just information, and care, not just choice?* To help patients feel safe to talk about obesity we created three **personas**. This helped to frame the discussion in a hypothetical situation. The personas were read aloud. Then, participants explored how the current tools help patients and physicians.

To facilitate this exploration, we created **dialogue prompters** (Figure 3), tools that create a space for interaction, reflection and generation of ideas. Dialogue prompters have pre-structured activities to foster collaboration.

Two **dialogue prompters** were created. The first prompter presents questions to foster reflection, such as 'Are all the categories in the 'bubbles' helping to unpack the stories in the Personas? In what way?'

A second dialogue prompter explored whether the goal-sheet helped the Personas plan change. This prompter included a **provotype** of the goal-planning tool. Provotypes support collaborative exploration at early stages of the design process, 'drawing out details of practice that may not emerge organically through questioning' (Erwin et al. 2018).

To explore changes in the bubbles and the timeline, we created another provotype (Figure 2).

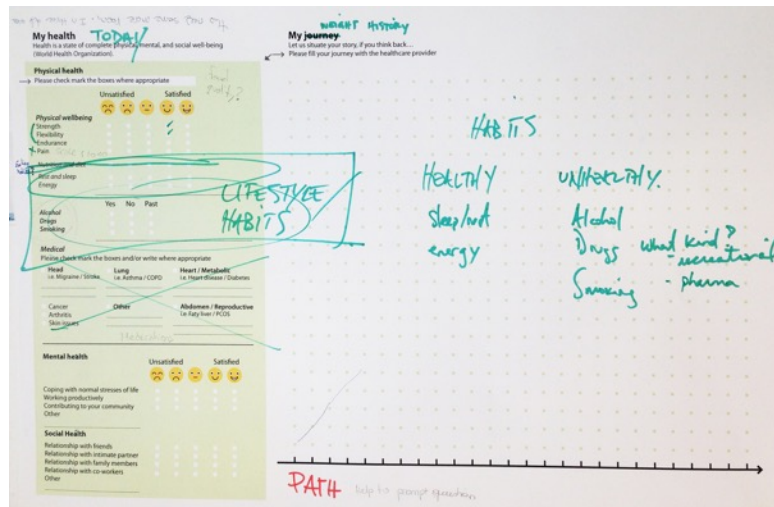


Figure 2. The provotype.

The other two **co-design workshops** helped understand the degree to which the first prototypes work, their perceived affordances or possible actions (Norman 2013) and to collaboratively envision how to improve them (Figure 3). The 10 participants were paired and grouped in two tables.



Figure 3. Participants collectively explore how to improve the prototypes.

We designed four **prototypes** based on 24 performance requirements (Fascara and Noël 2010) emerging from the data collected. Eight prototype iterations (Figure 4) were done. Prototypes helped focus the conversation, and reduce misinterpretations (Fascara and Noël 2017; Sanematsu and Cripe 2018).

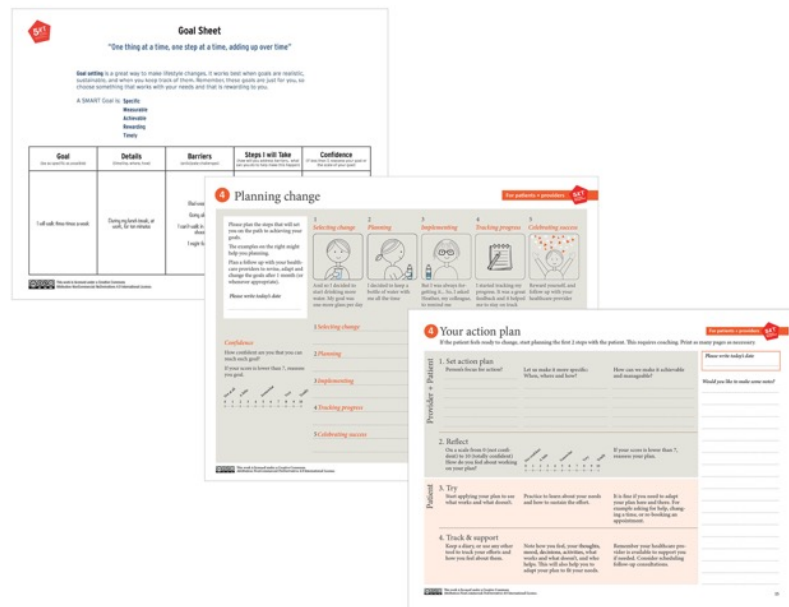


Figure 4. Iterative design process.

To enable participants collaboration in the design of the tools, it was necessary for them to try the tools. To achieve this, we used **role-playing**. The three **personas** used in the first workshop helped participants situate themselves in the story of a ‘constructed’ patient.

Two **dialogue prompters** helped participants propose change and adapt the tools to their needs. The dialogue prompters have pre-determined questions to investigate how the tools helped to foster conversation.

Data analysis

During the workshops verbatim notes were taken. The comments on the dialogue prompters were aggregated to the notes. The data was analyzed using affinity diagramming to identify themes (Beyer and Holzblatt 2017). Verbatim statements were written up on post-it notes and grouped based on their affinity. The affinity showed the scope of the users’ problems and helped develop design requirements.

During the co-creation notes were also taken while observing the role-playing. These findings were used to develop performance requirements to guide the design decisions.

Results

1. Understanding the design problem

The following findings emerged from **the observations**:

- Providers frequently introduced the conversation as being about 'health: physical, mental, spiritual.' However, the conversation was more focused on conditions. The tools should help understand the patients from a holistic point of view.
- Conversations are different, partly because of the patient's complexity, but share a common structure. The tools should provide structure but allow for different content and details.
- Topics that were not covered were what brings motivation and satisfaction; and who helps.
- The tools prompt, but there are things that only the provider can do, such as digging in, or working iteratively to re-define goals.
- Pointing occurred occasionally. The tools provide a common territory.

The first **co-design workshop**, helped gain an understanding of patients' needs, develop design requirements, create prototypes, and re-define the tools' content. Figure 5 illustrates main results of the co-analysis.

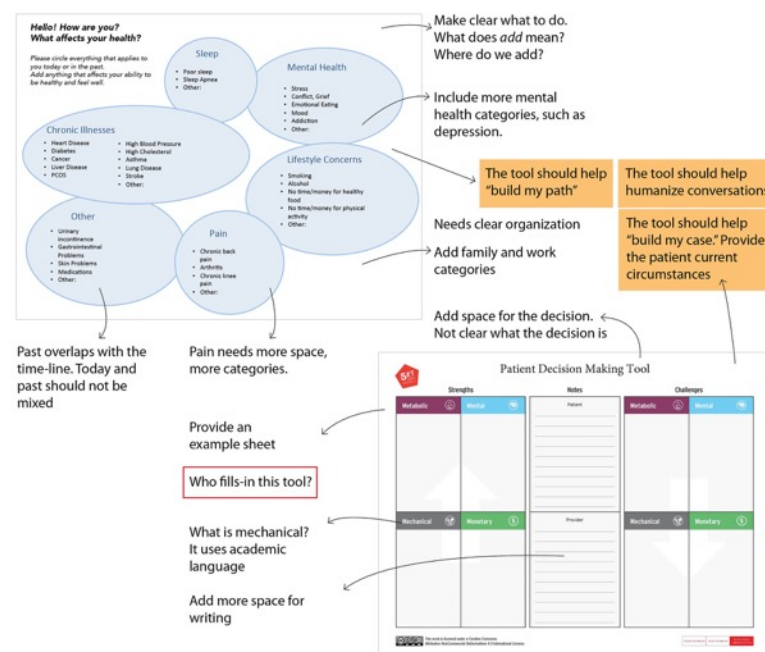


Figure 5.

Five main themes emerged. *Engaging patients in meaningful conversations*, refers to actions tools facilitate: engage, inquire, understand, inform, coach and plan. *Guiding through instructions*, relates to the need to clearly understand who the tool is for, and how to use it. *Providing a clear structure*, is about the need for the tools to be visually related; and have a clear visual organization. *Talking about personal life, not just medical stuff*, is about the need to talk about 'your family baggage' or 'work environment;' and not only medical conditions. *Monitoring and getting feedback*, refers to the

need for the tool to help monitor the plan; and for eventual support to discuss the plan. A participant stated: 'setting goals is fine, but if you don't get to the outcome what is the point.'

2. Co-designing the tools

Role-playing

Role-playing helped revealed what worked, and what didn't (Figure 6). The prototypes promoted engagement. Most participants figured out how the tools work.



Figure 6. Role-playing helped participants experience the prototypes.

The *personas* proved useful to create a safe space, but demanded some thinking. For example, participants needed to recreate part of the journey: 'It was probably when I was about 8 years old.'

Tool 1 *prototype*, was easier to use than the timeline. The timeline had little dots to help tracing the line. Users needed to figure about how to use the dots, in which direction to count pounds or years.

In tool 3, participants doubted who had to fill it in. Most participants had problems identifying the person's strengths and challenges. It was clear that it needed coaching through examples or training. This issue was mentioned during the first co-creation. Some providers invited patients to self-identify their strengths.

In tool 4, identifying goals was difficult. Some providers were quicker and more skillful than others at establishing possible areas for action.

Dialogue prompts

The dialogue prompts were effective at fostering collective thinking and helping participants made or propose changes. Table 2 presents the main changes.

Table 2

Tool 1	Tool 2	Tool 3	Tool 4
Show more connection between the different health factors	Use weight & health, nor one or the other	Change the planning area to one	Pictures are not useful. Use just 3 or 4 clear sentences
Add space for writing comments in all categories	Show a clear relationship between life event and impact on health	Change title to strengths & challenges	Change title to planning change
Add more functional aspects to the categories	Move the time-line to the middle	Add area for writing summary or brainstorm ideas	Guide more the steps, get to when and how
Use precise and clear labels for the categories	Instruct how to use the tool	Prompt brainstorming	Change the word goals. Too much pressure to plan goals
Make clear who fills-in the tool		Instruct to address readiness	Remove celebrating success. Some people might not get there
Use only 1 way to fill-in the tool		Remove mental, physical, and social labels	

Discussion

Diverse communication needs emerged between patients and healthcare professionals. Patients found the first prototype too medical and technical not helping to address their overall health. Health professionals needed the tool to cover more mental health and aspects like occupation and income.

The co-creation clarified that we needed to differentiate between what the tool should do from what the health professional should do. For example, the tool should *support the identification* of patients' strengths, but it is the *health professional who identifies* strengths. This requires training.

The steps to guide patients to plan action needed to be simple to avoid overwhelming them. If the tool to plan action was overwhelming, it affected the patients' capacity and confidence to plan and implement future actions.

Significant changes were made after the co-creations (Figure 7). The bubbles and the 4Ms were merged into tool 1. The strengths and challenges part of the 4Ms become tool 3. The book 'Think small' by Service and Gallagher provided the basis to change tool 4's planning approach. Instructions and examples were developed, this required re-watching the 9 videos. The tools are now a loop, it starts with where the patient is and want to be, and it ends with planning possible ways to get there.

Working iteratively to understand the users' needs and explore the problem/solution space is a very suitable approach for healthcare, where time with providers and patients is limited.

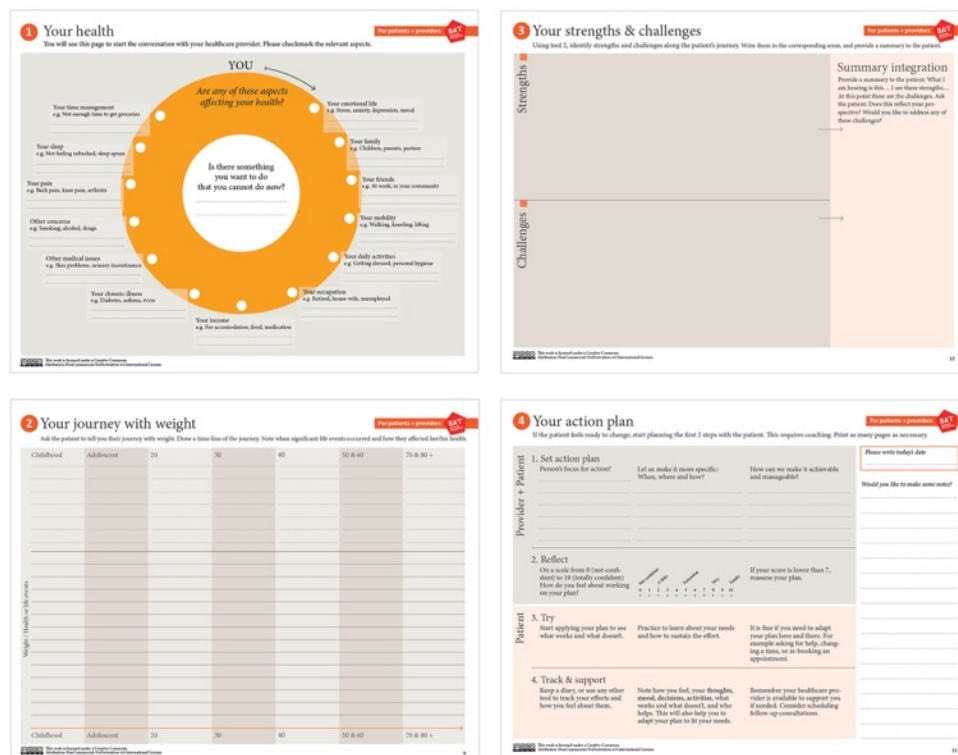


Figure 7. Final prototypes. Above left, tool 1 to understand where the patient is and want to be; below left, tool 2 to identify how significant life events affected weight and health; above right, tool 3 to identify strengths and challenges; below right, tool 4 to coach and create action plans.

Conclusion

As other studies show human-centred design helps achieve collaboration between patients, health professionals and researchers to design SDM tools that put patients and their complex care needs at the centre of the conversation (Boehmer et al. 2016; Garvelin et al. 2016). The participatory and iterative nature of human-centred design approach works well in healthcare.

The approach helps improve the tools by informing how to arrive at a patient-clinician interaction that offers conversation, not just information, and care, not just choice. To achieve this, the tools need to help understand the uniqueness and complexity of each case: the person behind the medical conditions. The tools should foster iterative inquiry to understand what is going on with a particular patient, to get to learn about the patient's circumstances to co-produce personalized care plans.

To arrive at conversations that offer care, tools need to support the science and art of medicine. The flexible, interpretative capacity that enables physicians and patients to co-decide the best action plan given the patient's circumstances (Montgomery 2006).

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Accepting an Assisted Sleep: Addressing barriers that influence engagement with Continuous Positive Air Pressure therapy through design.

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ABSTRACT *This paper addresses the question 'What are the initial experiences of people who use Continuous Positive Air Pressure (CPAP) therapy, and how can design address barriers that influence engagement within the first week of therapy?'*

Obstructive Sleep Apnoea (OSA) is a respiratory sleep condition that is characterized by a repetitive collapse of the upper airway during sleep, causing a lack of oxygen and build-up of carbon dioxide within the body. Left untreated, OSA can lead to serious medical conditions that may significantly reduce one's quality of life and risk early death. The primary treatment for OSA is Continuous Positive Air Pressure (CPAP) therapy. This is a machine that pumps pressurized air through a facial mask to keep the airway open during sleep. Even though CPAP is the most effective treatment for OSA, it is known to be burdensome and adherence is problematic.

This paper identifies the barriers that influence CPAP engagement through literature reviews, online surveys, cultural probes, and interviews with manufacturers, clinicians and CPAP users. Barriers include first impressions, product-related and social stigma, the ability to troubleshoot issues and the level of support, education and feedback present in the initial stages of therapy.

The outputs from this research focus on improving the user experience through design-based interventions that encourage self-management. First, a website that addresses education, support, customization and ability to troubleshoot issues. Second, an application that addresses feedback, support and troubleshooting issues. Third, customisable aspects that focus on personalization of the CPAP equipment through 3D knitting processes that develop fabric hose covers. Lastly packaging solutions that focus on the user's first impression, interaction and education about how to use the equipment. Concepts are reviewed by participants against their usability and relevance to the design criteria.

Keywords: Human centred design, user experience design, Obstructive Sleep Apnoea, Continuous Positive Air Pressure.

Introduction

This paper is a student led study that identifies the barriers that influence engagement with Continuous Positive Air Pressure therapy and as a design response, develops concepts that aim to address the barriers to improve engagement in the first week of therapy through intervention based encouragement.

Obstructive Sleep Apnoea (OSA)

Obstructive Sleep Apnoea (OSA) is a respiratory sleep condition that affects approximately 4% of the world's male population and 2% of the female population (Shapiro and Shapiro, 2010, 322). OSA is characterized by a repetitive partial or complete collapse of the upper airway dilator muscles during sleep, causing a lack of oxygen and a build-up of carbon dioxide within the body (Jordan et al. 2014, 737).

People with OSA experience sleep-related symptoms that include snoring, waking with a choking sensation, difficulty maintaining or initiating sleep, excessive fatigue or tiredness, and morning headaches (Jordan et al. 2014, 736). Performance related symptoms include daytime sleepiness, a higher risk of motor vehicle or work place accidents, and other health related implications such as a disturbance in mood, depression and cognitive impairments (Shapiro and Shapiro 2010, 321). People with untreated OSA are at risk of more serious medical issues such as cardiovascular, metabolic and neurocognitive conditions that may significantly reduce their quality of life or increase the risk of early death (Jordan et al. 2014).

Continuous Positive Air Pressure (CPAP)

Continuous Positive Air Pressure (CPAP) is an assistive machine that supplies continuous pressurized air, through either a facial or nasal mask, maintaining airway patency and prevent airway obstruction. This provides the user with sufficient inhalation of oxygen and exhalation of carbon dioxide during sleep, significantly reducing respiratory disturbances (Giles et al. 2006, 3).

Adherence

Even though CPAP is the most effective domestic therapy option for OSA because of its low risk and relative ease of use (Billings and Kapur 2013, 207), it is known to be burdensome and adherence is problematic (Shapiro and Shapiro 2010, 324). One in five people diagnosed with OSA refuse to initiate CPAP treatment completely. Of those who do try, half do not use it enough to gain the symptom and cardiovascular benefits; one year on, half of the patients would have abandoned CPAP completely (Billings and Kapur 2013, 207).

The importance of the first week of use

Studies suggest that there is a need for effective efforts to optimise adherence before or shortly after starting treatment (Jordan, et al. 2014, 737) as long-term adherence is significantly influenced by the initial short-term CPAP use (Somiah et al. 2012, 497). Studies suggest that patients who become non-adherent in the first few days of using CPAP therapy tend to remain non-adherent and refuse to persist in future (Weaver and Grunstein 2008, 173).

Past intervention studies

Past intervention studies to improve CPAP adherence range from a variety of methods including educational programmes, support and cognitive behavioural strategies. However, these responses lack design oriented approaches. CPAP adherence is a multifactorial clinical problem that requires similarly designed approaches, to effectively address barriers that influence engagement and adoption of CPAP therapy (Weaver and Sawyer 2010, 245). There is a need for the design of the experience in the first week to be addressed.

Methods

Research through design

This research aims to develop an understanding of the user experience, and develop designs that allow for self-management by considering the psychological impact of adopting a new lifestyle.

The methods applied in this research are chosen by their ability to develop an understanding of the barriers that influence people's engagement with CPAP therapy using Research through Design based on Design Criteria (Rodríguez Ramírez 2017). The criteria frame and support the development of designs that address the barriers identified. The refined design concepts are reflected against the criteria in discussion.

Semi Structured interviews

To develop an understanding of the experience of a new user, interviews are held with stakeholders involved in this process to identify their understanding of the experience and any touchpoints that can be addressed. Interviewees included;

A Clinician

Sleep Physiologist, 23+ years' experience as a Sleep Technologist, New Zealand (SP1)

Manufacturer representatives

- Interface Development Engineer (M1)
- Clinical Research Associate (M2)

CPAP users

- Male, 2+ years' experience with CPAP therapy (P1)
- Male, 2 weeks' experience with CPAP therapy (P2)
- Female, 1.5 years' experience with CPAP therapy (P3)
- Male, 1 weeks' experience with CPAP therapy (P4)
- Female, 2+ years' experience with CPAP therapy (P5)

Cultural probes

Cultural probes were given to participants to gather insightful information about their experiences using CPAP therapy without intruding in their home. Cultural probes encourage participation through self-documentation and reflection of personal experiences (Starkman and Chow n.d; Mattelmäki 2008) through set activities including writing a list of house rules, a love letter and a break up letter to their CPAP.



Figure 1: Cultural probe example

Online Surveys

To gather information from a wider scope of CPAP users, online surveys were used to identify the variation of experiences. The link to the survey was posted in a popular online OSA/CPAP support group, with 2200 members. Participants remained anonymous and provided key information about their experiences using CPAP.

Thematic analysis

The results from the data collected are analysed and collated into themes using thematic analysis (Braun and Clarke 2006).

Results

Barriers that influence engagement

Barriers	Factors associated with...	Explanation
First impressions	Treatment method.	Impressions and perceived value, initial experience using and when they receive equipment for the first time
Self-Efficacy	Patient, partner support and clinician support.	Cognitive and personality factors, health belief, intrinsic and extrinsic motivations to use the therapy.
Stigma	From diagnosis, and treatment method, product and social factors	The cumbersome lifestyle change. Product and social related stigma.
Support	Partner, family, clinician on-line and support groups.	From health professionals, partner, family, support groups and spousal acceptance.
Feedback	From the treatment method, physical and cognitive, clinical, applications and online support	Physical and cognitive adverse side effects, statistics, applications, reassurance, health professionals, partner and family.
Education	From online sources, clinician and packaging.	Provided from health professionals, equipment and packaging, online forums and websites.
Ability to troubleshoot issues	Delivery of information, physician, packaging,	Provided from health professionals, equipment user manuals and packaging, online forums

Figure 2: Analysis of the barriers that influence engagement

First impressions

First impressions are an important factor when delivering the equipment to the user. There needs to be consideration to the psychological impression that the therapy and equipment has on them, how it is received and expectations of the therapy.

Education and the ability to troubleshoot issues

Education has an important role in long-term engagement, where informed patients tend to be more motivated with CPAP therapy use (Van Zeller et al. 2013).

The accessibility of information is important for users to understand how to independently troubleshoot any issues, understand what to expect, and how to manage the therapy equipment. There is a need for education that addresses different mediums so the information delivered is manageable, and consistent as currently there is disconnection between manufacturers and clinicians. SP1 expresses that there are very few places that talk about the positives of CPAP therapy in lay language. Instead medical terminology is used, making the therapy seem overly complicated to the user. M1 states that clinicians often provide their own information to the patients to make it seem less complicated.

What to expect

Expectations are a reflection point for users when they begin the therapy. Not knowing what to expect can be overwhelming for the user. Aspects that need to be addressed include the apparatus in the bedroom, the time it takes to get the right mask and the correct air pressure, and to notice a difference in symptoms. SP1 states that people that think that it will work in a single night are doomed to failure as adopting CPAP therapy is a lifestyle change. If people understand the process, it helps them to get started knowing that it does not need to be right all at once.

Survey responses reiterate that knowing that the therapy takes time to feel the benefits, and to get used to the therapy makes a difference in accepting it. When asked what they would give to a new user, the responses were to persevere, and take time to adjust to the therapy, and get the right mask.

Apparatus in the bedroom

The association of stigma and CPAP therapy is both product related and social due to the medical aesthetic and the intrusive nature of the equipment. People cannot control the social stigma related to their condition. However, they can control whether they accept or reject the product related stigma associated with the therapy. Stigma is a factor that influences the way people celebrate, or hide their therapy. The cultural probe 'write a list of house rules' gave insight to this as P1 stated that the CPAP must 'Hide when somebody else comes'. During the interview the same

participant stated that 'if the cleaner comes I usually put the mask away as it doesn't particularly look that attractive, but I'd keep the machine in place'.

Support

Support from clinicians, online support groups and partner/family can be the decisional factor in engaging with therapy or not. People often seek support groups for guidance with issues, rather than talking to their clinician so when new users feel like they have an unrealistic pressure to get it right the first time. P1 in particular has not seen their clinician in over 4 years, so the motivation that to use the therapy is solely driven by health belief, despite explaining that they 'are probably not using their CPAP as much as they should'.

SP1 states that patient acceptance can be highly influenced by their partner's acceptance. Often noise from the machine, and mask can cause discomfort for the bed partner. Initially partners are used to waking to their partner having an apnoea, but when the machine makes unfamiliar noises it is hard to know what is ok and what is not.

Feedback

Feedback can be physical or cognitive, where some users rely on their statistics from their sleep and others rely on how they physically and emotionally feel after using CPAP therapy. Some machines have applications connected to them that provide immediate feedback from the machine, and others fully rely on the statistics sent to the clinician via the machine, that the user is unable to see unless they get a report.

Design Results

The design phase uses criteria developed from the touch points identified from the data collected (Figure 3). Different design approaches are generated through iterative modelling and prototyping.

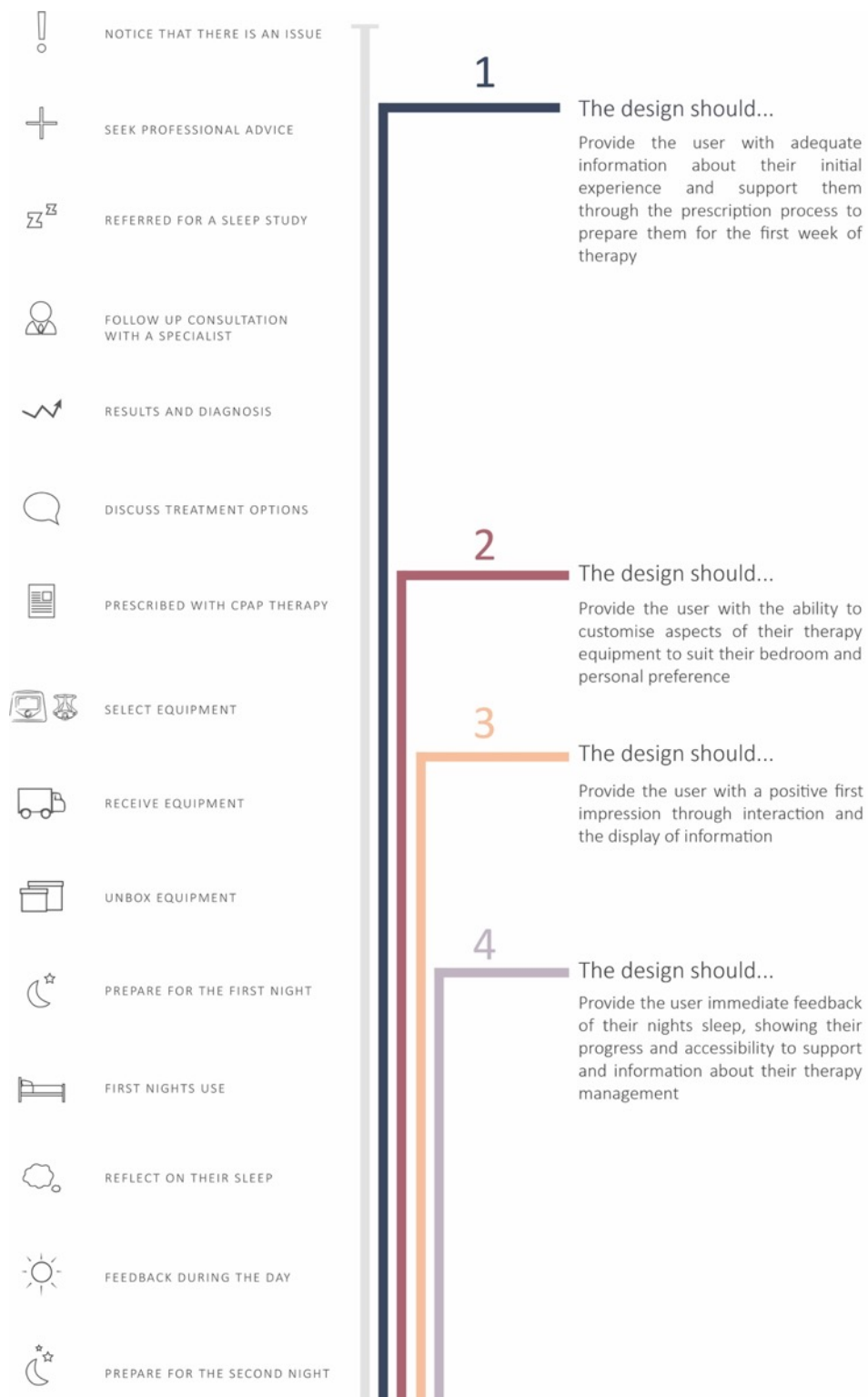


Figure 3: User journey of a new user with design criteria

The system

The aim of the designed system is to apply new educational processes and design applications that engage new CPAP users through interaction and self-management. By changing the focus from the tool that provides the therapy, but providing the user with the ability to self-manage through the delivery of information, customization and interaction. This research has addressed multiple barriers that are present in the user journey of a new CPAP user in the following concepts.

Website and mobile application



Figure 4: Mobile application interface

The website and application work in conjunction with each other. These concepts are structured by criteria 1 and 4 (Figure 3) and address first Impressions, education, feedback, and support.

These are informative ways of providing the user with adequate feedback and the connection to their results, medical professionals and support from authentic sources to avoid misinformation and misuse. Users are able to share experiences, statistics and goal setting to establish early use patterns and create a network of support with other users.

As a response Participant 5 stated that the feedback from the application will be valuable for them to manage their therapy effectively. All current sleep applications focus on the result – a good night sleep, and not the ongoing therapy management and areas that may influence their sleep effectiveness such as showering before bed, electric blanket use, or did they have alcohol, coffee or tea before bed. They expressed that sleep is part of their health, so it should be tracked like lifestyle a fitness applications. This mobile application allows for the user to log their symptoms, sleep hygiene along with their therapy statistics and goal setting.

3D Knitting

SP1 states that there is real value in having the hose inside of the bed with the patient. If they move around in the night and if it is in their personal space, then they will move with it instinctively, like moving a pillow. This reduces the risk of leaks, partner discomfort or wrapping themselves in the hose. 3D knitted hose covers address the second criteria in Figure 3. These allow users to customize their own cover to suit their personal taste. This addresses the stigma associated with the plastic in the bedroom, self-efficacy, and partner acceptance. The covers also keep the air warm preventing condensation and rainout, where the moisture build up in the hose blows through into the mask.



Figure 5: 3D knitted hose covers customized by Participant 4

Figure 5 shows the customization process for Participant 4 that particularly enjoyed customising the colour and pattern of the hose cover to suit their family's tartan. Participant 4 stated that 'it takes away the ridged, medical look of the hose'.

Packaging Design

People's initial reaction when they receive the equipment is to unpack it all at once, put on the mask and turn the machine on. The first instinct is to try it out, skipping the process of becoming familiar with the equipment and learning. P5 stated that 'reducing the information overload in the initial stages of treatment would make it less overwhelming'. The packaging aims to address the users first impression, improved perceived value, reduction of stigma and the gradual feed of information.



Figure 6: Interactive Packaging Design

The packaging concept (Figure 6) acts like a book in the way that it opens and displays the information and equipment to the user. Pop up books and similar precedents have driven the design to be a sophisticated interaction. Each phase of the interaction reveals key information specific to CPAP therapy management. The materials also encourage long term use for storage.

Reflection

Barrier	Website	Packaging	3D Knitted hose cover	Mobile Application
First Impressions		✓	✓	✓
Product related stigma		✓	✓	
Social stigma	✓		✓	✓
Delivery of information	✓			✓
Education	✓	✓		✓
Feedback	✓			✓
Support	✓			✓
Troubleshooting issues	✓	✓		✓
Apparatus in the home		✓	✓	
What to expect	✓			✓
Self-Management	✓	✓		✓

Figure 7: Analysis of the barriers that each concept addresses

Figure 7 expresses the different barriers addressed by each concept. With reflection on the system described, P5 stated that the system makes the therapy much more personal. Through slow learning, the system is less overwhelming and lets the user know what to expect, how to manage their therapy, and receive adequate feedback, creating a gradual lifestyle change. The personalization gives them the ability to own their therapy.

Conclusion

Design can influence people's engagement with therapy by not only focussing on the tool that provides the treatment, but by also expanding the focus to how people initially experience and manage the therapy. This allows the identification of important parts of the user experience, such as first impressions, the efficiency of support, education and feedback, stigma, and the ability for

users to troubleshoot issues. The key finding is the necessity to self-manage so new users are able to own their therapy.

This research has taken a speculative response that focuses on the intervention of CPAP therapy use through concepts that address the barriers as a designed experience.

There are limitations to the extent of this research through the skills and expertise of the researcher through participant sizes and ethics restraints. By improving user journey of a new CPAP user there is potential to improve the patient belief, and improve the motivation and investment of therapy use for effective and engaging therapy.

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To Play is Not a Taboo! Case Study of co-designing Open-ended Designed Table Games for including diverse users

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ABSTRACT Chronic conditions can have disruptive consequences on the conduction of daily activities, leading to depression, anxiety and ultimately social exclusion. Many design solutions attempt at supporting and facilitating the conduction of such daily activities but, rather often, these solutions follow top-down approaches, mainly focusing on the efficiency aspects, encountering low acceptance rate in the final user and not improving the overall well-being of the users. The artefacts here presented cover the double role of being both result of a methodology of co-designing open-ended bottom-up outcomes and, of stimulating research about the possibilities of using open-ended play as trigger for revalidation and social integration. The adopted methodology, generally through design, involved students of Industrial Design Engineering of UGent (Belgium), and is as follows: students of design engineering courses are asked to participate to a year-long co-design process, where end users with chronic conditions become active team members (1). Students are then asked to up-scale the obtained outcome into marketable projects (2) built upon several user-tests done with functional prototypes (3) and with main focus on the open-endedness of the outcomes. Two examples have been reported *here*: Memoro and AMFI, table games specifically designed in order to embrace the diversity of user by facilitating re-appropriation from the end-user, with the goal of decreasing rejection and taboos related to the users' conditions. First tests are promising, while future researches aims at further implementing the methodology and at testing the usefulness of the final Open-ended Design.

Keywords: open-ended design, open-ended play, participatory research, co-design, assistive devices, table games, methodology, education

Introduction

Chronic conditions can have disruptive consequences on the conduction of daily activities, leading to depression, anxiety and ultimately social exclusion (Bury 1982). Many design projects focus on how to facilitate the conduction of daily activities but, rather often, many solutions proposed follow top-down approaches, mainly focusing on the efficiency aspects, encountering low acceptance rate in the final user and not improving the overall well-being of the users (Couvreur 2013). Simultaneously, the material world created by industrial designers is meant to empower users, enabling new possibilities sometimes previously impossible. As written by Nelson 'we must design, because we are not perfect' (Nelson and Stolterman 2012, 13). In reality, sometimes products surrounding us don't empower us, they rather 'erode our sense of independence' (McDonagh and Thomas 2010) while transforming simple actions of our daily activities into hard if not impossible ones. Furthermore, many projects focus on implementing autonomy in daily actions such as hygiene, transportation, work, etc. In this case study special focus has been put on the specific activity of playing, this in fact has been proved in many ways to help people with chronic conditions in avoiding social exclusion and even improve their overall status and perception of well-being.

Design landscape: top-down and bottom-up

Nowadays, we could recognize the emergence of design for one project (i.e. DIY, hackings, etc.) as a reaction to lacking or to unfitting commercial solutions (Couvreur 2016; Couvreur and Goossens 2011). This phenomenon can be defined as products' adaptation, end-user development, design-after-design or community-driven development (Binswanger and Aiyar 2003; Ostuzzi et al. 2017; Fischer and Giaccardi 2006; Lieberman et al. 2006), and is represented in Figure 1 with the arrow descending from right to left. Sometimes the actors of this dynamic get involved during the design process conducted by companies, and/or their inventions become a trigger for products' innovation. This effect, the innovation paradigm represented in Figure 1 with the ascendant arrow from left to right, is defined as consumer, user-developed or lead users' innovations (Von Hippel 2005; Von Hippel, Ogawa, and de Jong 2011). Some studies focus on disabled users as potential lead users (Conradie et al. 2016; McDonagh and Thomas 2010), as they face challenges in the material world that might not be evident to others.

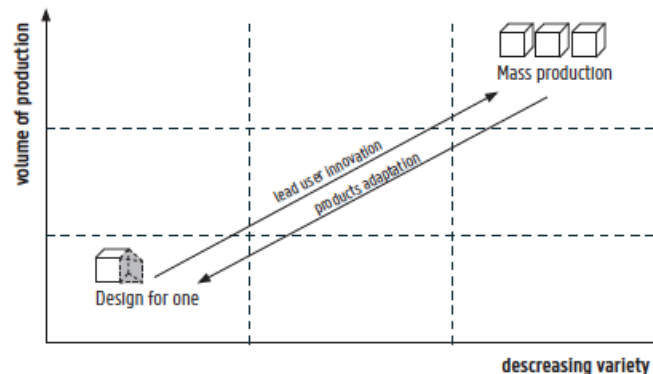


Figure 1: Dynamics of up-scaling personal innovations and adapting mass produced solutions

But in fact, even valuable design outcomes face rejection: on the one hand top-down standard solutions – created *for all* – might not reach the goodness of fit that is required, while on the other hand bottom-up local solutions – created *for one* – are hard to be adapted, because of their very contextual nature. In both cases problems can be recognized on that these design outcomes are generally not designed with a '*real use*' perspective (meaning the dynamic use that occurs in time) and, in case they are, it is often under the belief that only expected things will happen. A possible way to facilitate re-appropriations and adaptations from the end users is what has been defined as Open-ended Design.

Open-ended Design

'An Open-ended Design (OeD) is seen as a project able to change, according to the changing context. Open-ended Design can also be defined as suboptimal, error-friendly (Manzini 2010), unfinished, Wabi Sabi (Juniper 2011) contextual, context-dependent and is characterized by its inner flexibility due to the voluntary incomplete definition of its features, also defined as its *imperfection*' (Ostuzzi 2017).

In other words, Open-ended Design are seen as products intentionally left open (in some aspects, defined as *contextual*) in order to facilitate re-appropriation from the end-users. In this perspective games could be designed in order to embrace the diversity of users and conditions. This case study has been then focused on the way these games can be designed, referring with this to the methodology and procedure. The following image (Figure 2) shows the overall goal of the research: to start with intensive co-design projects (for one) and to up-scale them into marketable products without losing the capability of fitting *each* specific user.

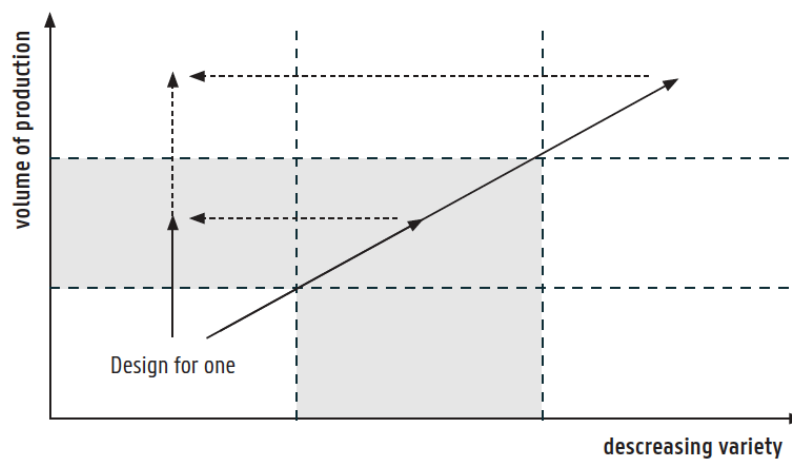


Figure 2: Goal of the study is to first co-design 'design for one' solutions and then try to up-scale them into marketable outcomes, trying to embrace the high level of variety of users potentially engaged.

Methodology: co-designing open-ended outcomes

The work of the designer cannot be considered as separated from the users he/she is aiming at. Often in fact, design has the goal of enhancing self-expression of others (the users), definable as *other-expression* (Nelson 1994). Co-creation can be seen as any act of collective creativity, while co-design can be seen as the collective creativity applied throughout the whole design process (Sanders and Stappers 2008). In this scenario the users move from being subjects of the design, as for User Centred Design approaches, to be active partners. A particular focus should be put in the role of non-human participants, such as visualizations, mock-ups and prototypes (Ehn 2008), considered as thinking tools to be used through the process in order to trigger reflections, to support conversations, to bind different stakeholders together (Björgvinsson, Ehn, and Hillgren 2010), rather than merely describing the object of design itself.

In this educational project the co-creation teams are composed of three main actors: designers, occupational therapists and end users which follows the same team definition described in the project D4E1 (designforeveryone.howest.be). Several projects explored similar processes (Hermans 2014; Hermans 2015;/// enablingthefuture.org, digitalforming.com, last accessed on June 2018///) and prove, generally, this hands-on approach allows end users to 'adapt their assumptions through the engagement with design activities within their own local environment' (Couvreux et al. 2013, 67; Mugge, Schoormans, and Schifferstein 2009).

As mentioned the two cases reported here belong to a broader educational project, taking place at the Ghent University, Campus Kortrijk, Belgium. In this project students are trained to first co-design the game to address one specific user (1) and then to upscale the outcome into a marketable product (2). Students were asked to continuously test with communities of users, in order to highlight differences and commonalities between users. Specifically, in the first phase specific focus has to be put in what have been defined as *contextual variables* since, in the second

phase, these variables become the ground where the open-endedness expresses itself. These contextual attributes have been defined as 'elements that need to change, in order to fit in the new context of use' (Ostuzzi 2017).



Figure 3: Testing Memoro with the design team, occupational therapists and users with dementia. The test was developed in a retirement home in Belgium.



Figure 4: Testing AMFI with the design team, occupational therapists and end users with chronic conditions. The test was developed in the rehabilitation centrum of UZ (University Hospital) of Gent, Belgium.

Results: AMFI and Memoro

The final results of Memoro and AMFI are displayed respectively in Figure 6 and 7.

Memoro, 'a company about accompany' is designed by Lucas Wyffels, Respens Bavo, and Lefevre Stefan with and for users with dementia. 'Memoro is a reminiscence tile-based board game for people with dementia and their family, friends, ... processed in a fun face lift. While laying tiles to build a road, cards are picked with a specific reminiscence theme. This theme stimulates the senses and engages every player into storytelling with each other about the fun topics on the cards. It is the total package for a fun afternoon full of untold stories. Memoro helps stimulate interaction to reinforce the connection between the person with dementia and their family' (text from the business plan of the company Camano). The openness of the product lies in its use, in fact, it built upon personal stories and memories, which would be fully unimaginable by the designer him/herself.

AMFI, 'unlimited joy' is designed by Dries Dekersgieter, Thomas Gruwez, and Charles Degeyter with and for users with limited motoric skills. 'AMFI is a board game where the players only need to perform simple, rudimental movements to operate it. Nevertheless, the game can be played quite tactical and it presents a good level of complexity. [...] In AMFI to decrease the stigma common for many commercial products, a co-design of personalized handles can be done, by adopting digital production techniques' (text from the business plan of the company AMFI). The openness of the product, differently from the previous one, is created during production through a personalized approach to what has been considered the *contextual* design aspect (specifically colours, shape and proportions of the handle).



Figure 5: Memoro, comprehensive of tiles, scents, cards and packaging



Figure 6: AMFI, with different handles specifically designed for different users

Both cases, comprehensive of business plans, are focused on embracing diversity of users and experiences, trying to decrease the stigma and improve participation to game sessions. Both games achieved recognitions in public contests, specifically AMFI won first prize in SBP Vlajo Awards 2016 and Memoro first prize in Bizidee in Kortrijk.

Conclusions

This research focuses on a possible methodology to create and up-scale Open-ended Design (OeD) outcomes, specifically of games to be used by and with people with chronic conditions. The reasons behind the search for such open-ended devices are multiple, but mainly justified by the aim of embracing diversity of users, improving usability and foster the *togetherness* of playing. The presented games have been tested on a small scale, but will need further investigations to better understand the actual satisfaction connected with the use. At the same time also the methodology of first designing 'contextual' design solutions and then up-scaling them with an Open-ended Design perspective should be further developed especially with the focus of translating what is now only an educational attempt, a good practice for designers.

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Design, Behaviour change and long term conditions: The impact of demonstrating design skills to adolescents with chronic pain

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This paper reports on part of a research-through-design PhD study. This study sought to understand if participatory workshops to share design skills and approaches with adolescents with chronic pain could have an impact on their management abilities and behaviours.

Academics have long sought to understand, define and articulate the skills that designers possess and how they 'do' designing. In recent literature there is increasing interest in how these skills might be shared and utilized outside of design professions in areas such as; education, business management, policy-making and as a means of empowering citizens. Supporters of this application of design typically associate the use of design practices and process to innovation, problem-solving, business strategy, behaviour change and resourcefulness.

There is an emergent precedent in health sectors to use design this way. Literature suggests it is a young field with scope to develop knowledge within it. Knowledge gaps include; developing an understanding of the impact of sharing design practices and approaches, exploring different types of engagement with a variety of stakeholders to identify how they might benefit from this approach, and to further develop methods and exemplars of delivery. Furthermore, a better understanding of healthcare contexts, languages, modes of operation and philosophical frames is required.

A mixed methods analysis was used to understand the impact of the workshops. Initial findings indicate positive changes in mind-sets associated with design approaches, greater understanding of design skills and subsequent application to management abilities and behaviours.

This paper will present the methods used in, and findings from, the research. It will also reflect on the complexities of conducting this type of design-led project in a healthcare context, where there can be conflicting worldviews on evidence and knowledge, and strict ethical procedures to adhere to.

Background

Recent years have seen an increased demand for design methods and approaches within healthcare development and research (Chamberlain, Wolstenholme and Dexter 2015; Horne 2013; Baeck 2013; Design Council 2004). This has been linked to a need for increased innovation, collaborative ways of working (Cottam and Leadbeater 2004), new ways of thinking on complex problems (Design council 2008) and better involvement of stakeholders (Wolstenholme et al 2014).

As a result, designers working in these cross-sector, interdisciplinary collaborations are often faced with a range of multifaceted issues. These 'wicked' problems can be open, complex and multi-dimensional, without a clear or optimal answer (Rittel and Webber 1973; Buchanan 1992). An area that demonstrates the potential of design's impact in relation to these types of problems, is behaviour change in long-term condition (LTC) management (Craig 2017).

An estimated 30% of the population live with a LTC. This has a large impact on the UK National Health Service (NHS) with 70% of the NHS spend, 80% of GP consultations and 60% of hospital bed days attributed to them (Ellins and Coulter 2005; Coulter, Robert and Dixon 2013). The support and management of those with a LTC is a priority for the NHS, who recognize that effective management of health and wellbeing results in better quality of life for patients, reduced use of NHS resources and in turn, reduced costs (Coulter, Robert and Dixon 2013).

The best way to support those with a LTC can be classed as a wicked problem; it is complex and multi-factorial and dependent on; age, the condition, physical and mental health and financial and social issues (Ellins and Coulter 2005; Lau-Walker and Thompson 2009). A review by the Health Foundation (2011) recognizes that certain behaviours improve health outcomes and therefore condition management programmes based upon changing behaviours are likely to have success.

There has been interest in recent years to understand how design can encourage this behaviour change in LTCs (Wolstenholme et al 2014; Craig and Chamberlain 2017). In 2009, the Royal Society for the encouragement of arts, manufactures and commerce (RSA) proposed that design is a form of resourcefulness. Believing that if other citizens had the skills to be resourceful (and designers shared their skills to support this) then it might impact upon their ability to create behaviour change and overcome challenges (Campbell 2009).

Consecutive studies by Craig et al. (2013) and Wolstenholme et al. (2014) have explored this hypothesis with patients who have a spinal cord injury. The first, in response to the RSA, undertook exploratory inpatient Design Thinking sessions at the Spinal injuries centre in Sheffield. The second, introduced Design Thinking sessions as part of inpatient rehabilitation offered at the same unit. Both developed activities that demonstrated design methods and designer's skills in areas such as; Creative thinking, communication, problem-solving and prototyping. They aimed to empower patients and give them confidence to take control of their environment and future plans as they learned to manage life with their injuries.

Results from the second study showed key themes of learning and experience. Quantitative data showed statistically significant, positive changes on self-efficacy measures. Participants enjoyed the sessions, changed their perspective on problems, reported better creative thinking skills and increased confidence to try new ideas. This suggests that design workshops as part of rehabilitation can support behaviour change and are a new, novel approach that needs further investigation, particularly to explore transferability to other areas of healthcare.

This PhD study built on these recommendations and sought to develop further understanding by applying the concept to another clinical area. A scoping review identified that literature on LTCs suggests adolescents are an understudied population. An estimated 15-20% of adolescents have a significant ongoing healthcare need that relates to a LTC (Sawyer and Aroni 2005). Yet, of all age groups in the UK, it's the only one that had not seen significant health improvements over the past three decades, with LTC outcomes worse than in adults (DoH, 2012).

In 2012 the Department of Health recommended that children and young people (adolescents) should be equipped with skills and knowledge to support them to navigate the complexities of life, manage LTCs and improve future health outcomes (DoH, 2012). They recognize that this would support current health and provide an opportunity to invest in positively impacting on a generation. Health behaviours and patterns established during this time underpin a person's adult health and are likely to continue (Sawyer et al 2012; Lemer, Cheung and Davies 2014).

Through identification of this gap in the literature, this study sought to understand if workshops to share design skills with adolescents would impact on their behaviours and condition management.

Study Design

Building on the two previous studies, a programme of two workshops were designed and developed for adolescents who were receiving pain management (PM) through Sheffield Children's Hospital (SCH). Each workshop demonstrated design methods and practices and lasted three hours. Analysis sought to understand their impact on PM behaviours.

The aim was not to teach someone to be a designer or how to go through a design process. It was to introduce skills and build confidence to use them. It proposed that this might help them to approach the world like a designer would and apply those skills to challenges they might face.

Design techniques were used to illustrate and demonstrate these skills through experiential activities. Some were adapted and developed from various sources that included (Craig et al 2013; Campbell 2011; Wolstenholme et al 2014). In the interests of keeping the sessions interactive, the sessions focused around activities, video clips and short explanations. There was purposefully no PowerPoint, instead presentation and sharing by the participants was encouraged.



Figure 1: Participants during workshop one presenting their outputs from an activity on perspective.

The study recognized 10 key designs skills from the literature (Cross 2006; 2007; Lawson 2004 and Dorst 2009). The focus of the first workshop was how designers see and experience things, with emphasis on; Observation, Perspective, Questioning, Knowledge and Understanding, and Opportunity. The focus of the second workshop was how designers imagine and create things, with emphasis on; Communication, Prototyping, Optimism/Creative Confidence, Experimenting, Learning through failure.



Figure 2: Participants during one of the second workshops.

The study was conducted as research and gained full NHS ethical approval on the 20th January 2017.

Analysis

A mixed-methods approach was used for analysis. A Qualitative Likert survey was used to compare abilities and confidences in design related tasks. Participants rated themselves from 'strongly agree' to 'strongly disagree' across 12 statements. The survey was completed at the beginning of the first workshop and at end of the second.

Two qualitative measures were used. The first was a short questionnaire of eight questions. It enquired about their experience of the sessions and if they could see a change to any behaviours since. The second measure was a semi-structured interview. Both measures were subjected to a content analysis.

Findings

The workshops took place during the holidays, with two weeks between them. 15 adolescents were recruited, however four of these dropped out between workshops. Overall, there were 11 complete Likert scale data sets, 7 questionnaire responses and two interview transcripts for analysis.

Data from the Likert scale showed 12% negative responses, 64% positive responses and 24% had no change. Half of those negative responses can be attributed to one participant. Overall the average change for each statement was positive.

Qualitative data shows that the experience of attending was positive and engaging, it provided a unique approach to PM and has enabled them to develop new mind sets and skills.

Many of the participants gave examples of how these newly developed skills were being used, such as; in explaining their pain to others, within school or to consider new ways to get back to sport.

'the whole time I've just been focused on my end goal..... but the workshop helps you kind of, not adapt but look at things from kind of hobbies that I've had and really enjoyed. From netball, I enjoyed the fitness aspect, I'm really competitive so I enjoyed that so then I've taken that and taken up other kind of sports and hobbies that I probably didn't think about before'

Other less specific examples included; out-of-the-box PM techniques, developing confidence to give things a go and seeing things from another's perspective.

Another finding is the positive aspect of being in a group with others who have the same experience. For many this was the first opportunity they had to meet someone with their condition. Finally, the adolescents enjoyed learning new skills and strategies without focusing specifically on their problems or practically applying the skills to themselves in the session.

Something this analysis highlights are the difficulties communicating this type of design practice to those outside the field. Participants' were unsure exactly what to expect from the sessions (although they recognized that a degree of experiential knowledge was required to fully

understand) yet found it hard to articulate to friends and family exactly what had happened despite the positive experience.

Finally, the data shows no direct impact on pain levels but this is not surprising, as this was not the intention of the study.

Discussion

This study has demonstrated that this type of design workshop is transferrable to other clinical areas, and has a positive impact on adolescents' mindsets. Adolescents reported an increase in confidence, development of design mindsets, the ability to see things from new perspectives and saw areas where these skills had a direct impact on their PM behaviours. In discussion with the therapists, some linked the studies success to opening a young person's worldview, as many become 'stuck' or fixed in their ways of thinking.

Research by Sawyer (2012, 2005) and the Department of Health (2012) on the current understanding of how to best support adolescents to manage conditions presents a field where there is still much to be understood. This study adds to this discussion; the findings suggest that learning about design skills and practice can support condition management. It also supports the notion that peer support and group sessions are positive for those who have LTC's. In the current PM service, there are no group interventions. As an outcome of this work, the team are in talks to develop these.

Further novelty was that there was no focus on the participants' condition. The activities demonstrated and gave the participants an opportunity to learn the skills but did not directly relate them to their pain. The adolescents found this helpful. It demonstrated the benefit of allowing a safe space to master a skill before applying to one's own situation. Furthermore, as this application was not part of the workshop it suggests the transferability of the design skills learned, and potentially demonstrates that the methods transcend the ideas and that adolescents can make their own links. This learning fits nicely within therapy for PM, which does not focus on 'removing' pain, instead, it seeks to enable patients to continue to engage with normal life, cope with their pain and facilitate recovery to as high of a level as possible (Sheffield Children's Hospital, n.d).

However, running these workshops as a design researcher in a healthcare environment was not without difficulties. This study was run as a piece of research; therefore it was subject to the ethical procedures of research in the NHS, alongside University ethics and local site protocols at SCH. Gaining ethical approval for this study was a lengthy process. Differences in worldviews, approaches to research and language barriers proved to be difficult to navigate. There were difficulties in clearly articulating the study whilst ensuring that the research stayed true to design methods. Much of the documentation did not allow for the reflexive, iterative nature of design research, requiring exact information on the amount of sessions and what would happen at each. It took careful negotiation to write an application that satisfied both fields. Overall, including

amendments, ethical approval took 18 months. This had a drastic impact on the time to recruit and run the study, as a result, only one round of workshops was completed (the original study design included multiple rounds to explore various ways of running and implementing the methods).

Alongside ethics the researcher spent time conducting a period of design ethnography. The aim was to build a relationship with the PM team to understand the context that the workshops fit within. Furthermore, building a relationship with the team supported the sessions and recruitment. This was successful and led to a body of work with the team to develop the service. More information on this is written up elsewhere (Partridge 2017).

Something that spans the ethical procedures, design ethnography and the findings of the adolescent workshops, are the difficulties communicating this type of design practice within healthcare. Peoples experiences of the term design vary widely, and many have little to no understanding of the methods and skills that designers apply. Even those who have been through the workshops found it difficult to explain the sessions to others, suggesting there is a degree of tacit learning within them. The concern is that if not articulated correctly, in a way that can be comprehended by healthcare practitioners, the value of design methods and designers will not be understood. As a result, this sort of study will not reach those who would most benefit from it and design in healthcare will not reach its full potential.

Conclusions

This work has clearly demonstrated the benefits that learning through and about design practice can have on adolescents with a LTC. It adds to a growing body of knowledge on how best to support adolescents and suggests that this could be a new and novel approach. It aligns with previous research by Craig and Wolstenholme demonstrating that the theory can cross contexts, although more work is needed to look at wider populations and the potential to apply it across conditions.

However, delays to ethical approvals limited the scope of the study and the ability to follow up patients over longer time periods. Further effort needs to look at the longitudinal effects of this type of intervention and explore optimal delivery and integration into current management support. This is particularly important as with current financial pressures on the NHS, there is scope to understand how these sessions could be delivered that would reduce costs, but maintain the outputs.

Finally, this research has demonstrated the difficulties of trying to conduct this type of work in healthcare, particularly when classed as research. More needs to be done within wider design and healthcare research to support the understandings of design practice and demonstrate its value.

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Challenges in developing a co-designed patient experience toolkit using action research and design iteration cycles

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ABSTRACT ONLY *Positive patient experience (PE) is considered a key indicator of high-quality healthcare delivery. Yet the ability to use PE data to drive change, improvement and innovation is notoriously challenging. This paper reports on phase two of a project to understand and enhance how hospital staff are enabled to use PE data through a series of co-design workshops. The workshops contributed to the development of a toolkit that has been trialled and developed in six hospital settings through action research cycles.*

The aim of these cycles was to capture how implementation of the toolkit works in practice and understand what changes might be required. Despite successful co-design workshops to create shared understanding and develop the initial toolkit, researchers found that outside of the co-design workshop environment, it was not used as planned. Complexities with staff time and resources and challenges of accessing data required the action researchers to move from a support/ training role to a facilitation role.

Through this process, the action researchers concluded that the toolkit would not work on its own to support ward teams through such a process and would always require some 'expert facilitation'. This created a shift in the end user of the toolkit. Rather than working with the ward teams to explore if the toolkit could develop to overcome some of these challenges, the designers worked closely with the action researchers to develop the toolkit for an expert facilitator to use with ward teams.

This paper reports on the initial findings of these cycles and the subsequent changes to the toolkit to accommodate these shifts in use. We reflect on the impact that the change in role of the researchers had on the implementation and discuss this in the context of our experiences as designers engaging in a co-design methodology within a healthcare setting.

Keywords: Action research, Toolkit design, co-design

Co-designing the waiting room of the future: Considering a combination of the spatial, service, and technology layer through the lens of patients' emotions

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ABSTRACT Here, we report on the findings and outcomes of the Waiting Room of the Future Project which was conducted in collaboration with a local community health care provider (Access Health and Community). The aim of the provider is to lead innovative health provision in the region and as part of this to have a waiting room where their patients feel welcomed and cared-for. Previous research has shown that the experiences that patients have while waiting for their appointment has a direct impact on overall patient satisfaction levels. However, studies concerning waiting rooms in healthcare settings often provide little emphasis on emotional responses of stakeholders. Hence, the research presented here focuses on patients' emotions as starting point for designing the patient experience in the waiting room. We demonstrate our emotion-led design approach and associated co-design methods. A photo documentation kit and a focus group, were used to ascertain future goals and aspired emotions from staff surrounding service delivery. Surveys distributed in the ACCESS H&C waiting room were used to discern how patients would like to feel when engaging with technology and services on-site, but also the acceptance of technologies in regards to scheduling, information provision and health self-management. We illustrate our findings concerning stakeholder experiences using goal models and rich picture mappings and how they were translated into spatial and application design. In considering the spatial, service, and technology layers in one study simultaneously we can compile a holistic waiting room concept that stretches beyond the physical space and caters to user needs across each layer. Lastly, we offer a variety of co-creative methods providing people a strong voice embedded in a design approach that allows key stakeholder to communicate their emotions. The waiting room concept is currently realised by our industry partner on their site.

Keywords: spatial health care design, co-design, waiting room, emotional goals, health technology design

Introduction

In this research we collaborated with a local health care provider in Melbourne, Victoria called Access, Health and Community (ACCESS H&C). ACCESS H&C has centres that are located across three municipalities. The centre focused on in this research hosts a wide range of health service specialists ranging from general practitioners, dietitians, physiotherapists, dentists, counsellors and chiropractors (see Figure 1). The objective of this research is to create solutions that will enable ACCESS H&C to deliver innovative health provisions in the region. Our main strategy to achieve this is to create an environment that aligns with their patients' emotional needs. Emphasizing emotions as the leading driver in this study, the investigators asked: How do patients want to feel in the health care waiting room of the future? To answer this question, a multidisciplinary team consisting of a Human-Computer Interaction (HCI) specialist, a digital media designer, a service designer and an interior architect collaborated and worked closely with the service provider. The HCI designer managed the project; the digital designer developed digital prototypes; the service designer developed co-design materials and the interior architect translated the findings into spatial designs supported by a Master's student team.

The Waiting Room as a Space

A survey of 1360 people conducted by The Australia Institute (Dennis & Fear, 2010) found that 44.1% had avoided going to the doctor because they were "too busy", while 31.3% didn't go because it was "too hard to get an appointment". These results affirm that lengthy wait and lead times are not just a mild inconvenience, but a barrier to healthcare. Unsurprisingly, the 'wait' also has a significant impact on patient satisfaction, dropping as perceived waiting time increases (Yeddula 2012). Additionally, this perceived wait time is detrimentally affected when the patient is found to be waiting for unknown reasons, with anxiety, in discomfort, or in an unproductive state and for an unspecified time (Karaca 2011). The pressure of mounting queues also permeates through to physicians, who need to deal with conditions from a broad range of patients within a limited timeframe. Sherwin et al. (2013) highlight that these limited consultation timeframes can lead to patients feeling rushed, and with unanswered questions or incomplete information. Staff too can experience low morale (Knight 2005) derived from the difficulties in managing patient wait times, queues, and complaints in the face of dwindling patient satisfaction. Healthcare services can be unpredictable. Often, emergency scenarios are given priority which can push out waiting times. Interestingly, research into patient satisfaction finds that it is not just the time spent waiting, but the perceived wait time of the patients that causes frustration (Carroll 2012). Perceived waiting time is key to improving the patient experience and satisfaction.

Emotions

Research has focused on the waiting room environment in relation to perceived quality of care (Arneill 2002), staff efficiency (Ulrich et al. 2008) and the influence of design to create functional environments that communicate brand attributes (Cooke 1983). This research approaches the practice of designing waiting rooms by understanding how a user would prefer to feel when experiencing a waiting room. If not addressed, the negative emotional responses endured whilst waiting for an appointment can cause anxiety, stress and influence the patient's overall satisfaction with the visit. However, it is not only during a visit that patients may feel emotionally distressed. Kuusela et al. (2013) explain that older adults, in particular, often leave their appointment feeling anxious because they find it hard to remember the doctor's instructions and absorb health information. This presents an opportunity for studies that focus on the role of emotions within the space of the waiting room and opportunities for implementing technologies and innovative services.

Technologies

The display of waiting times on digital signage can help alleviate the perception of inflated wait times and anxiety generated by unknown wait times (Karaca 2011; Nemschoff 2015). Such notifications can be personalized and expanded to smartphones, which may provide patients with the ability to book appointments, locate the room (Labarre 2011) or check-in for an appointment once close to the clinic (Kennedy 2016). Also, SMS has proven to be just as effective at reducing missed appointments via postal or call reminders whilst being the most economical communication form for patient reminders (Free 2013). Gordon et al. (2015) demonstrated that clinics can extend such messaging services to deliver medically relevant information to the patient or caregivers post consultation; reporting that this type of open communication received 'high levels of satisfaction' from users (Gordon et al. 2015).

Chan (2014) and Rolls (2011) illustrate that kiosks both assist with queue management and can provide information specific to individual patient needs. Flat-panel monitors, can also be utilized as responsive health education tools that can be updated unlike printed materials where wait times are long enough to facilitate the message (Larsson 2015). Productive use of patients' time correlates directly to patient satisfaction levels and perceived wait durations (Yeddula 2012; Karaca 2011).

In sum, a wide range of problems in the waiting room can affect staff and patient experiences. In order to address these problems, we entered a co-design process with key stakeholders focussing on emotion-led design.

Co-designing for positive emotions

A photo-documentation method ('snap- it' – see figure 1) was used to explore service barriers, workflow (in)efficiencies and future directions, while a focus group elicited refined emotions suitable for developing a goal model based on these barriers. Lastly, a 1:20 model of the waiting room was constructed to spatially position key research insights. Through all methods, three themes for potential intervention were explored: spatial, technology and lastly service design.



Figure 1: ACCESS H&C building and The SNAPIT* photo-documentation kit instructions

Photo-documentation Kit and Focus Group

Seven of the nine staff returned photographs as a way of capturing stories and building narrative for the focus group. Based on the results of the photo-documentation kit, five ACCESS H&C staff discussed uncovered barriers, efficiencies and inefficiencies and were asked to share their ideas, and feelings with a specific focus on service delivery, technology adoption, spatial design, and future goals for re-design.

Example for staff narrative

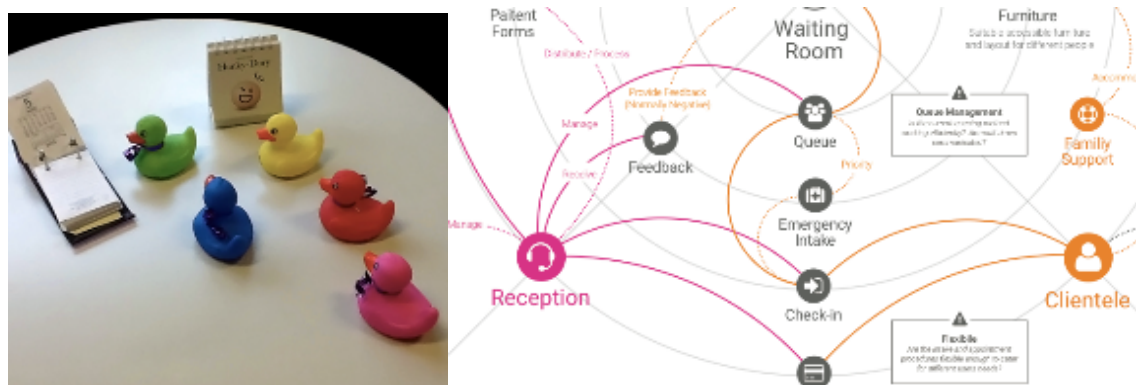


Figure 2: Photo from kit and Rich Picture

Figure 2 demonstrates how photographs from the kit were used as rich stimulants to discuss complex service barriers and their associated emotions. The stories and insights found throughout these activities often shared relationships with multiple stakeholders, and were not isolated. The rich picture (Figure 2 right) demonstrates these complex relationships. Participants

preferred a more accessible model that moves away from the largely 'one size-fits-all approach' to a more tailored service in the future. A future goal for ACCESS H&C according to participating staff should be one where 'Patients can Access the services in a number of ways and receive care for their priority need in a timely way' (See figure 2 left opposed to a 'waiting in one line model'). Also, 'patients who need to see multiple care providers receive coordinated, and integrated care' and 'patients are prioritized based on their needs'.

Digital Barriers

It became evident that multiple patient information technology systems fail to communicate with each other when staff members are required to manage appointment requests for patients needing to access multiple services. In accordance with Trauma Informed Care, it was suggested by one participant that the lack of a self-check-in kiosk can make patients feel stressed or anxious not having privacy but being forced to speak with the receptionist. The flat screen TV was seen as positive or negative depending on what information was screened and their relevance to the people in the waiting area.

Service Barriers

The biggest barrier to services was that clients are put on multiple waiting lists and access services based on the length of the waiting list, rather than the clients' priority need. Staff commented that brochures and information is poorly organized or out-of-date, hence making it difficult for patients to find information relevant to them. The amount of information material was considered over-stimulating. Also, reception staff are put under a great deal of pressure to help patients locate services that are often difficult to find, for instance, one participant commented on regularly being asked to find the call number cards for nursing services. One staff member presented a currently used low-tech communication system between patient, doctor, and reception staff. After each appointment, a clinician indicates on a pre-printed note the fees, funding source and care provider as well as details for booking the next appointment and passes it to reception to process. This interaction facilitates communication between the clinician and reception staff, enhances efficiency and overcomes some of the digital inefficiencies.

Spatial barriers

Spatial features such as the width of the corridor from the reception to the medical suites cause access difficulties for people using prams or wheelchairs and for general flow of people (figure 3). Reception staff often needs to direct patients to the bathrooms, out of view from the reception desk. Distraction was also presented as a spatial inefficiency for reception staff who 'have to watch the door slowly close to ensure no one else enters' having to play a secondary role as security staff. The height of the reception desk excludes people in wheelchairs. Also, the spatial location of the reception desk enables other patients who are waiting for an appointment to overhear private patient details of those who are in conversation with reception staff. The door to the reception area opens straight onto a busy road, causing concern for children while parents are checking in at

reception or completing forms. It was noted that 'it can feel like parents are not welcome in our service due to the lack of available parent change rooms near the reception area and, that the children's waiting area is not very inviting' (figure 3). Further many patients using wheelchairs 'park' in the children's play area for easy access to treatment rooms, cutting off access for children. There is no private room for a distressed or unwell patient to wait in, away from other patients. It was shown that the only private waiting area, doubles as the Needle and Syringe Room (NSP, figure 3): 'However it is not ideal for an individual experiencing trauma given the potentially confronting nature of the NSP information and disposal bin'. Finally, patients are required to wait at the doors prior to 8am until reception opens even during bad weather.



Figure 3. Narrow pathways, dual use of needle and syringe room and kids play area

Goal model with focus on emotions

In the focus group the narratives were further unpacked considering three distinct goals; Do, Be and Feel Goals (Table 1). For instance, when discussing multiple patient data systems that do not communicate with each other, it was suggested that the healthcare service provider should do 'one health record and shared care plans', that are to be coordinated with individual patient needs and experiences. This would enable Access Health and Community staff to feel productive and useful as well as deliver a feeling of 'My Place' to patients.

Table 1. Do, Be and Feel Goals brainstormed in focus group

DO	BE	FEEL
Create one health record	Best practice	My Place
Share care plans	Coordinated	Welcoming
Work person centred	Client centred	Interactive
Enable consumer engagement	Pathway driven	Efficient
Welcome patients	Expert Accessible	Holistic
Communicate information	Streamlined	Productive, Useful
Provide flexibility	Responsive	Cared About
	Equitable	
	Tailored	

These categories supported the development on the emotional goal model. Figure 4 presents a broad landscape of preferred emotions by the staff ACCESS H&C for their patients.

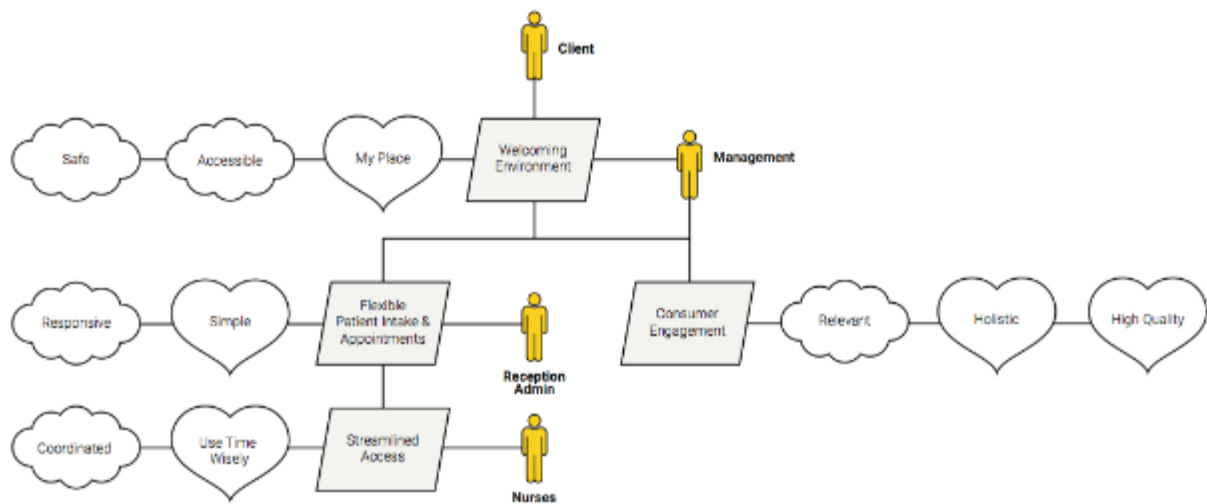


Figure 4: Goal Model - Hearts show desired emotions in the waiting room

Patient surveys

A total of 70 paper and 26 digital surveys were completed by patients about (i) current and preferred emotions and technology use in the waiting room and (ii) giving and receiving information from ACCESS H&C.

Patients wanted to feel welcomed and comfortable. It was communicated that a 'more private waiting area' would enhance client comfort. Self-check-in technology was considered a faceless option, suggesting that many clients appreciate personal interactions with reception staff and within their overall experience in the waiting room. The participants split into two groups of clients who wanted to do nothing or wanted to be productive. With the latter group there was a strong emphasis on the use of technology during wait times, namely using their phones to do work, use apps, or watch television. These would appreciate free Wi-Fi. Strong emphasis was also placed on technology being used to alert patients to changes or delays in their appointments. The majority of participants would like ACCESS H&C to help them take a more active role in their own health journey. However, participants did not feel as strongly when compared to the provision of tailored health information. A digital application was the most desirable format for patient self-management. There is consensus amongst most participants that if they knew the reason for appointments running late they would not mind as much which is consistent with the literature.

1:20 Model

A 1:20 Scale model of the ACCESS H&C waiting room was constructed (Figure 5). After responses were collected from all staff and clients at ACCESS H&C, a clear image emerged defining the spatial problems associated with the waiting room space categorized in emotional, physical and service oriented themes.



Figure 5: Goal Model - Hearts show desired emotions in the waiting room

Outcomes

Technology Design

The application is a tool to encourage patients to become more active in managing their personal health and improve overall communication with ACCESS H&C. The application has been built as fully functioning prototype based on the screen designs (Figure 6) of four design students (Design Honours). A vital feature, this application enables patients to view their appointment calendar, book, cancel and reschedule appointments with ACCESS H&C. As with the data collected during the surveys, patients wanted to use technology to manage their appointments and schedules. Furthermore, one feature allows patients to input their health statistics (weight, blood pressure etc.), enabling better communication with their doctor. The main benefit to tracking personal health information means that patients can review their progress and feel motivated to change/continue their healthy habits. Follow up care is a place to see referrals, access results and most importantly view a written version of doctor's instructions as verbal instruction are easily misunderstood or misinterpreted.

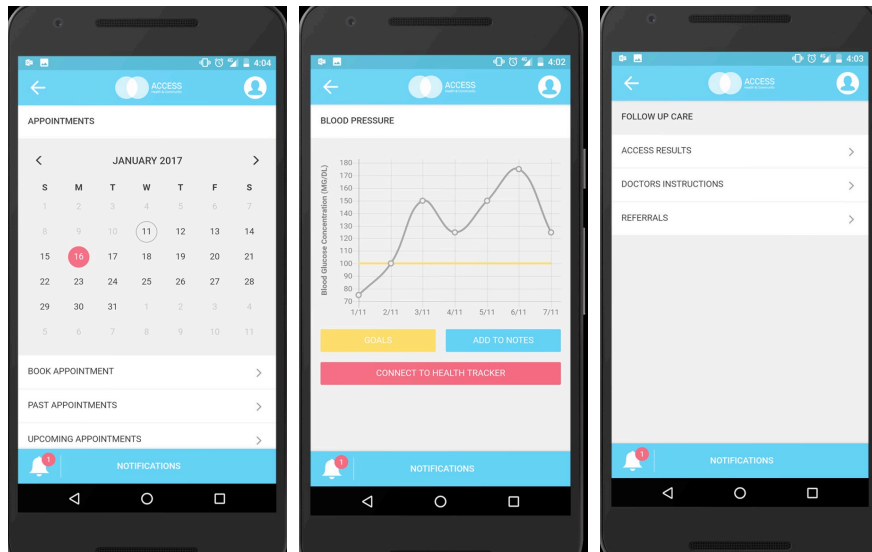


Figure 6: Appointments, Track Your Health and Follow Up Care as main functions of the app

Spatial Design

The spatial design was realised by students from the Bachelor of Interior Architecture (Hons.) program. In a first studio, 16 students developed a concept for the waiting room based on the goal modelling and the published research report. The students aimed to isolate principal problems of flow and circulation, universal access requirements and the need to provide a welcoming atmosphere. Four selected schemes were further developed in a second studio with focus on what was most important for the new waiting room design – namely the position and accessibility of the reception desk (see figure 7).



Figure 7: The entry view – final concept

Students were given a set of empathy provoking exercises through mobility devices and ageing suits in a full scale model of the waiting room that was set up in their classroom space. The students reported that this exercise was fundamental to their understanding of the different user groups of the waiting room as they each role-played being patient, carer and staff. Staff and executive agreed on the strongest scheme but also indicated key features from the others that they wanted included. Three students (Fiona Nowland, Chrissa Drosopoulos and Sarah Tucker) then worked in close collaboration with Flavia Marcello to refine the design to a single project that was approved for execution (see figure 8). It is anticipated that construction will commence in 2019.



Figure 8: Final design – view from reception desk area (different heights)

Conclusions

The Waiting Room of the Future project considers the diverse and complex landscape of the standard health care service waiting room. Involving multiple stakeholder groups, the project reaches well beyond the physical space of the waiting room into the lives of patients and medical service processes alike. The research team explored how this interaction and time spent could be facilitated in both supporting technology and spatial considerations that better meets the needs and emotions of patients and helps health care providers to deliver innovative and efficient health services.

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Valuing the design process in hiv prevention, diagnosis and stigma

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ABSTRACT A group of health workers and designers teamed up to develop novel ways to respond to HIV prevention, diagnosis, and HIV-stigma challenges. They integrated creative, participatory, user-centred design skills with scientific and clinical expertise to address emerging challenges. This paper explains how this interdisciplinary collaboration evolved, reflecting on how a design centred approach is valued and influences collaboration and outcomes in health projects. The research explores three projects in which design tools and methods such as user workshops, user journeys, scenarios, personas and interaction mockups were employed.

Project one aimed to develop a pilot service to encourage HIV self-testing among men who have sex with men (MSM). It included a series of design workshops involving members of the LGBT community and People Living with HIV (PLWH). The final design involved the building and testing of a bespoke vending machine to distribute free self-test kits, and of its digital interface. Project two aimed to develop a programme/campaign to increase HIV testing rates in general practice surgeries in Brighton and Hove. Project three, intended to reduce HIV stigma and discrimination using digital resources disseminated via social media platforms.

The paper identifies critical aspects emerging from the collaborative design process, shows how it is valued by health workers and demonstrates how the utilization of a design centred approach enables creative responses and facilitates collaboration and user involvement in the context of HIV prevention, diagnosis and treatment.

Keywords: design, health, HIV, collaboration, design process, interdisciplinary

Introduction

Advances in the management of HIV have transformed HIV disease from a fatal condition to a chronic disease with a life expectancy similar to that of the general population (Katz and Maughan-Brown 2017).

The introduction of antiretroviral therapy and pre and pro exposure prophylaxis has had a significant impact on the improvement of the life quality of people living with HIV and helped in controlling the spreading of HIV. As a result of these developments and other prevention strategies, the incidence of HIV in the United Kingdom is decreasing, Public Health England (2017).

However, information about how these advances have transformed HIV have not been disseminated. HIV stigma remains a significant problem for people living with HIV and remains a barrier to testing, preventing key populations from accessing diagnosis and treatment services. Data from Public Health England (2016) suggest that there are over 13.000 people in the UK that are unaware they are HIV positive.

Although there has been a substantial increase in testing options available to MSM (Men who have sex with men), they still face barriers hindering access to testing including stigma, confidentiality concerns and health service issues such as delays getting an appointment in clinics for testing. Similarly, misinformation, prejudice and ignorance in broad sectors of the population lead to the stigmatization of individuals living with HIV, depriving them of a regular and fulfilling life.

This state of affairs reveals the need for a creative approach beyond traditional medical research boundaries. Interdisciplinary collaboration between health professionals and designers seems to be a reasonable approach to address the complex and socially laden issues of HIV diagnosis and stigmatization.

The benefits and shortcomings of collaboration between designers and scientists (included medics) have been studied in the context of scientific research (Peralta 2013). There is a plethora of scholarly research reporting individual cases of collaboration between designer and doctors, but little evidence of it in the context of HIV research.

Some of the few existing examples include the work of Bennett et al. (2006) exploring participatory design methods with participants as co-designers of an HIV/AIDS visual campaign in Kenya, and the work of Van Deventer, Robert, and Wright (2016) examining co-design methods involving mothers of HIV positive children and health care workers to improve healthcare services. These investigations look at the value of participatory design approaches, but do not reflect on the design process as a whole, or discuss the collaborative process between designers and health workers.

This research responds to this gap by reporting on how health professionals and designers can team up to address the challenges presented by HIV diagnosis and stigmatization, making explicit

the value of the design process within this collaboration, arguing that designers and health experts disciplinary roles are complementary and favour the success of collaborative endeavour.

Although there are many potential ways of describing the design process, work by Dorst and Dijkhuis (1995) assumes that the design process is formed by all the interconnected actions designers carry on to generate a design proposal. It adheres to Stolterman and Nelson's (2012, 75) characterization of it as 'both systemic (integrative and interconnected) and systematic (methodical, sequential, and episodic)'. However, this paper recognizes that the design process is not necessarily a sequence of events, but rather a 'System of spaces [...] [that] demarcate different sorts of related activities that together form the continuum of innovation' Brown (2008, 4).

Method

This research draws its conclusions from the views of a team of HIV experts, clinicians, designers and a social sciences researcher who have, for the first time, engaged in a four year collaboration with two designers in three projects as illustrated below:

HIV PROJECTS & TEAM MEMBERSHIP

PROJECT \ TEAM MEMBERS	Designer A	Designer B	HIV Expert A	HIV Expert B	HIV Expert C	Clinician GP A	Clinician GP B	Social sciences Researcher	Patients Representative
1 Pilot project of a Digital Vending Machine for distribution of HIV Self- Testing kits	✓	✓	✓	✓	✓				
2 Development of a programme to increase HIV testing rates in general practice surgeries in Brighton & Hove	✓	✓	✓	✓	✓	✓	✓		
3 Using digital platforms for a campaign to reduce HIV stigma and discrimination	✓	✓	✓	✓				✓	✓

Table 1: HIV projects and membership

The data from the HIV experts and clinicians was obtained through individual written interviews. They were carried out via email, and the interviewees had the opportunity of asking questions before submitting their answers.

Using open-ended questions, the interviews were designed to explore the interviewees' views about their **experience** of working with designers, their thoughts about designers' **expertise** and **working practices**, and the **value and usefulness** of working with designers.

Data was also collected during participant observation (as the researchers of this investigations are the same designers of the collaboration) and discussion sessions between them.

The projects

Three projects were carried out during four years, as illustrated in figure 1.

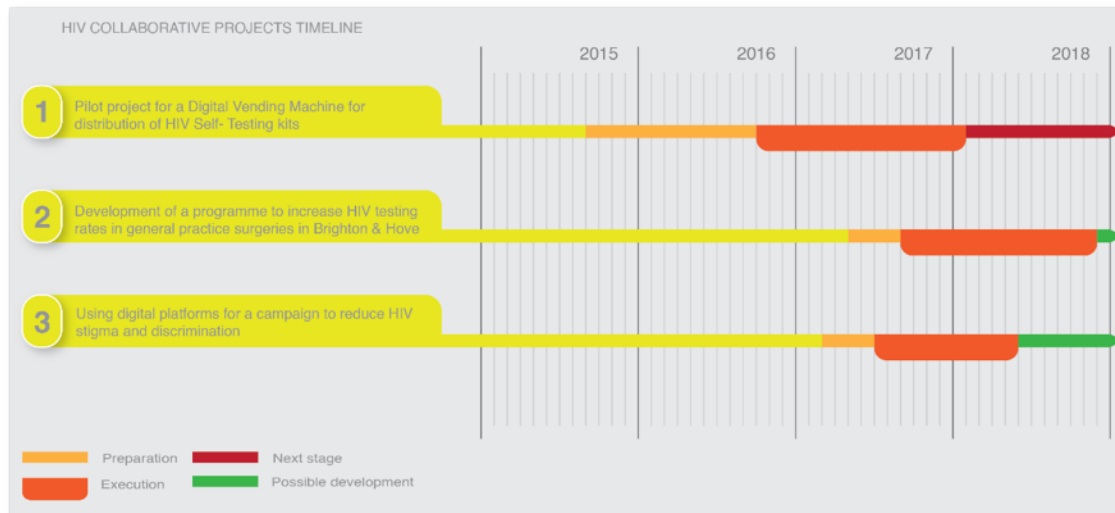


Figure 1. HIV collaborative projects timeline

Project 1 Pilot project for a Digital Vending Machine for distribution of HIV Self-Testing kits

This project aimed to enable the procurement of HIV self-test kits through vending machines in popular venues to high-risk MSM. It involved the design, customization, installation and testing of an HIV self-testing kit vending machine, and of a user support platform. The project development team included four HIV medicine experts and two designers with experience in product, interaction and services design.

Design process

The design process started with the outline of a design brief, followed by the development of initial visual concepts (to be embedded in the machine interface) to encourage the use the machine, and a proposal for its interface. After this, participatory design workshops with members from the LGBT community to evaluate and improve the visual material and the machine interface took place. The final design of the machine layout and its interface was developed, followed by the design of leaflets to inform patients what to do after testing. The design process concluded with the design and production of screen-based seasonal promotional posters.

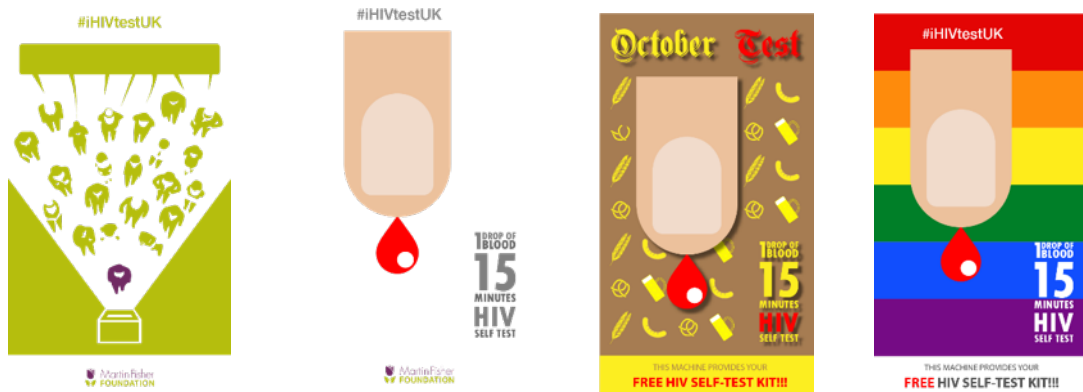


Figure 2. Examples of visual elements for machine promotion



Figure 3. Vending machine in the context

Project 2 Development of a programme to increase HIV testing rates in general practice surgeries in Brighton and Hove.

The project intended to develop a pilot programme to support behaviour change around HIV testing in the general practice workforce, encouraging GP patients to test for HIV. The programme was developed in three GP surgeries located in Brighton and Hove by two clinician champions working alongside a team of HIV expert clinicians and designers. After the team realised that the potential increment in HIV testing through GP practices would strain testing labs' capacity beyond their limit, the project refocused on the creation of a lobbying campaign addressed to

stakeholders and decision makers, to promote the advantages of the programme, and secure additional funding.

Design Process

After outlining a design brief, designers carried out non-participant observations in three GP practices. They observed patient behaviours in reception and waiting areas, witnessed live blood sampling and interviewed nurses and phlebotomists. Designers created a patient/user journey and designed alternatives for a campaign aiming to incentivise patient requests for HIV test, based on visual material and new protocols of interaction, including the development of a campaign 'motto' and a logo. As the clinicians learnt from the labs' difficulties to respond to an increased amount of tests, they refocused priorities. Then the designers, based on their patient/user journey, developed an animation to explain the proposed changes in blood testing protocols suggested by the clinicians.

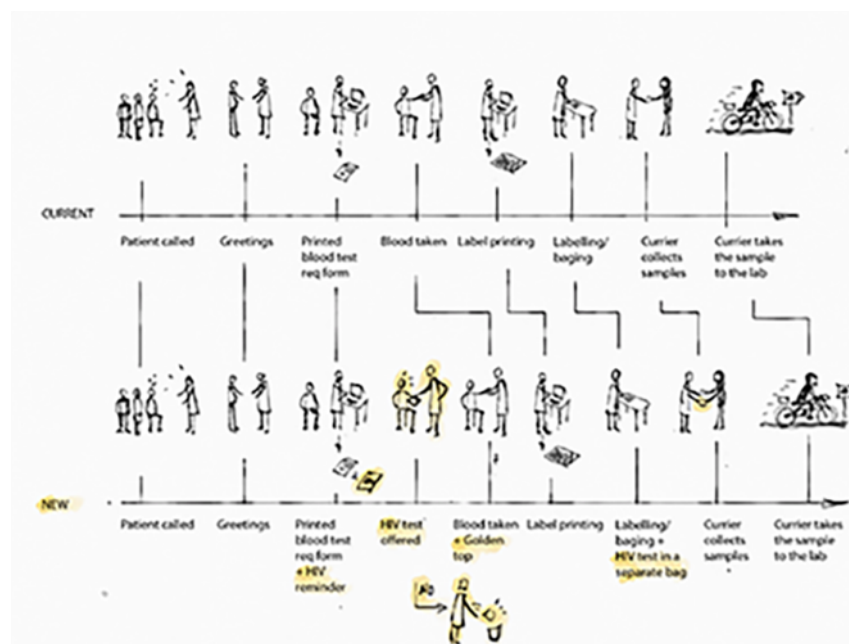


Figure 4. Diagram of the current and proposed patient/user journey



Figure 5. GPs campaign visual material proposals

Project 3 Using digital platforms for a campaign to reduce HIV stigma and discrimination

The project aims to reduce HIV-stigma by creating a digital anti-stigma campaign relevant to the general population, including illustration, animation and video. The content of videos and campaign messages are the result of a series of participatory design workshops with people living with HIV and from the general population.

The project team is formed by three HIV expert clinicians, one social scientist, two designers specialized in product/service design and a patient representative living with HIV.



Figure 6. Illustration by a designer of a workshop participant's insight

Design Process

It started with three participatory workshops where people living with HIV and members of the general population expressed their experience and views about HIV stigma. Using design tools such as Personas, scenario building, storyboard writing and cartoon drawing, participants develop key ideas and scenarios which became the basis for the campaign, and for the designers' concepts and scripts for the campaign videos. Designers defined guidelines for the video producers, briefs for the illustration and animation team. Alongside the patient representative, designers also created other campaign elements such as pins, T-shirts, fliers, etc., and visual material for social media.

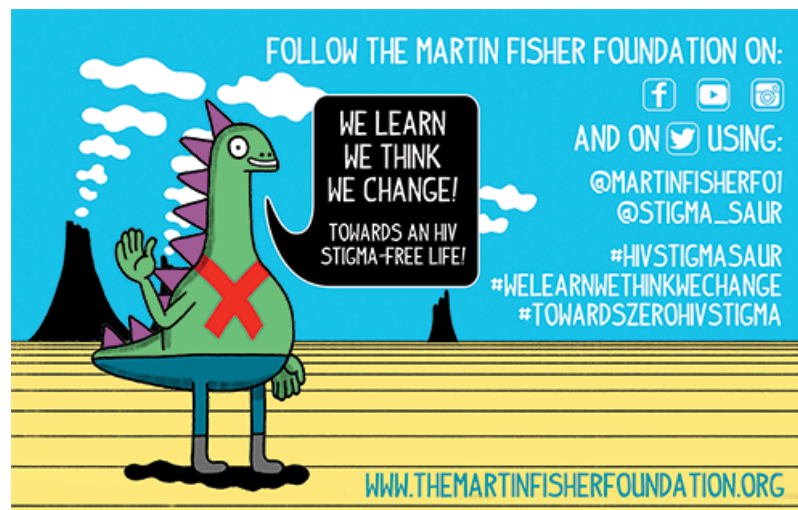


Figure 7. Campaign character 'The HIV Stigmasaur' in a promotional flyer.

Results

The research results show medics perceptions of their **experience** of working with designers, their views about designers **expertise and working practices**, and their appreciation of the **value and usefulness** of design and the design process.

Perceptions about how different was for them to work with designers in comparison to work with colleagues from their disciplinary area (experience)

HIV experts perceived noticeable differences in working with designers. For example, one of them said that it opened his mind to a different world, noticing that designers creative focus contrasts with doctors', which is centred on practicalities and 'technical stuff'.

Other clinician explained that working with designers enables doctors to have a say on the design of materials and on what is the best moment to 'get them across to patients'. He described the experience as an iterative process of development.

Another doctor observed that working with designers requires extra time to explain what they are trying to achieve, what is possible, and what clinical aspects are relevant. Relatedly, other doctor commented on the designers' lack of technical vocabulary and the need for doctors to speak to designers in 'lay' terms about medical concepts.

Other doctors highlighted how designers make look things 'professional' and how they learnt from them the importance and complexity of visual communication. She also noticed how designers seem to have a 'greater need to understand [processes]'.

Views on the design process and how it influenced their collaborative project (working practices/value/usefulness)

Most doctors comments on the design process focused on its usefulness or about specific parts of it. A doctor found interesting the use of research with users (through workshops) to underpin design work. Similarly, another doctor commented on how designers acquired knowledge of user journeys based on first-hand observations.

Even if doctors seem not to know much about the design process, they recognized the importance of it in the projects. This becomes evident in statements such as 'now, every time we need to develop something, we always think, oh, do we need a designer?'

Perceptions on what designers know and what they do (expertise)

Doctors were unsure about what designers know, but they recognized some of their skills:

- making medical information accessible and appealing to services user.
- translating medics' ideas into a design
- being the interface between clinical staff and patient, giving patients a better understanding of medical issues
- 'targeting materials' to achieve project's goals based on their good understanding of projects' goals
- Noticing if things look right or not
- Doing 'lots of research/communication before producing the end product [to ensure] it is fit.'

They also named some of the tools designers employed:

- Digital printing and drawing.
- Co-design workshops
- Props and make-ups

Ideas about the main challenges of collaborating with designers (experience)

Doctors identified several challenges to collaboration. They expressed problems about logistics such as finding suitable meeting time and premises. They highlighted the importance of understanding 'each other's work pressures [and the] need to have clear timescales of meetings given business of diaries'. They also stated the need for having regular communication, and face to face meetings, especially when discussing designs.

Medics underlined the importance of ensuring designers understand the project 'background' and are made aware of the project context and issues. Medics noted that differences in language (including technical vocabulary) and assumptions by doctors about designers knowing what they (the doctors) know could be problematic.

Qualification of their experience of working with designers (value/usefulness)

Medics qualified their experience of working with designers as positive, using words such as fun, exciting, rewarding and interesting. They referred to the effect the collaboration produced on them as enlightening and eye and mind opening. They also reflected its usefulness, describing it as a learning, helpful and constructive experience.

They linked their evaluation to certain designers' traits such as attention to detail, thoughtfulness, clarity, knowledgeability and professionalism, mentioning designers readiness to challenge the team when appropriate.

Perceptions of the influence that working with designers might have had on their ways of working and thinking (value/usefulness)

Medics reported that working with designers have changed their way of thinking and approach to work, noticing how they now look at patients interactions with the health system as identifiable and mappable processes. They also acknowledged the importance of involving and consulting with patients before changes are made. As expressed by one of the clinicians, there is a 'need to

understand the process (however simple it might seem – there are always extra insights to be uncovered) and involve patients - always’.

Doctors have also changed their communication approach, giving more importance to the use of visual materials when interacting with other colleagues and project stakeholders. A one them states, ‘I recognise that when it comes to learning, visual aids and videos are much better at getting the point across than just talking to people! Also having material and logos make your project look important - and people are more likely to take notice with an eye-catching logo and professional material.’

Discussion

The findings of this paper show how working with designers can be perceived as a positive experience by medics, how different but complementary designer and medics expertise is, and how useful design can be to address issues related to HIV prevention, diagnosis and stigma.

The experience

Collaborating with designers is not something HIV doctors are used to. However, the findings reveal doctors’ positive outlook about it, as it brings them new and complementary skills to help to realise their ideas, exposing them to fresh and different points of view, which also supports the improvement of their ideas and the generation of new ones.

Even if designers and scientists learn from each other during collaboration, the findings show that both doctors and designers continue performing within their respective disciplinary boundaries. However, there are cross-disciplinary influences, especially when designers and doctors adopt each other languages. This is also noticeable, as stated by some of the doctors, in their progressive adoption of the designer’s process and system thinking.

This research has also shown that the initial lack of a common working language between designers and medics is a barrier to collaboration in HIV related project, and that time and effort is required by doctors and designers to overcome it. While doctors need to find less technical ways of expressing medicine-related themes, the designers should attempt to explain their specialized vocabulary to doctors, especially about their tools and processes.

Different and complementary skills

It is apparent that design skills are complementary to those of medics. This can be understood by considering the work medics do in the HIV context. Other than seeing patients and undertaking scientific research, doctors are often involved in the development of initiatives for the improvement of the quality of the service they provide, and the pursuit of behavioural change in patients, health workers and the general population. These activities not only require expert

knowledge of HIV but a deep understanding of how their patients interact with the health service and the society.

In this sense, designers' user centred approach and skills are useful and complementary to doctor's, as they enable the understanding of patients as service users. Participatory design workshops, personas, scenario building and storyboard development, give doctors and designers access to patients experience and opinions.

It is also important to consider that some of the innovative ideas medics may have probably come from their day to day experiences and subject knowledge but might not have been sufficiently considered regarding the systems they are part of or the processual implications they might have. Designers system thinking skills, combined with a service design approach complements the experience and knowledge of doctors making available tools such as user journeys and experience mapping, to render doctors' ideas compatible with existing or future systems and processes.

Another aspect of this complimentary skills match can be explained by highlighting the processes by which doctors undertake their development activities. Any initiative of change they might want to pursue needs to go through a rigorous vetting process, where scientific, practical, ethical, institutional and economic considerations are paramount. This involves the procurement of research-based written evidence to justify their initiatives, and a series of communication activities to present their ideas to colleagues, patients, and other stakeholders. Designers' ability to develop visual material not only helps them to convey their ideas in a more precise manner but adds an element of professionalism to their presentations that can, as one of the medics expressed, increase credibility. An analogy that might sum up the value of the design process in HIV research is the one of a puzzle (collaborative endeavour), where all pieces (doctors and designers skills) complement each other; figure 8 illustrates this.

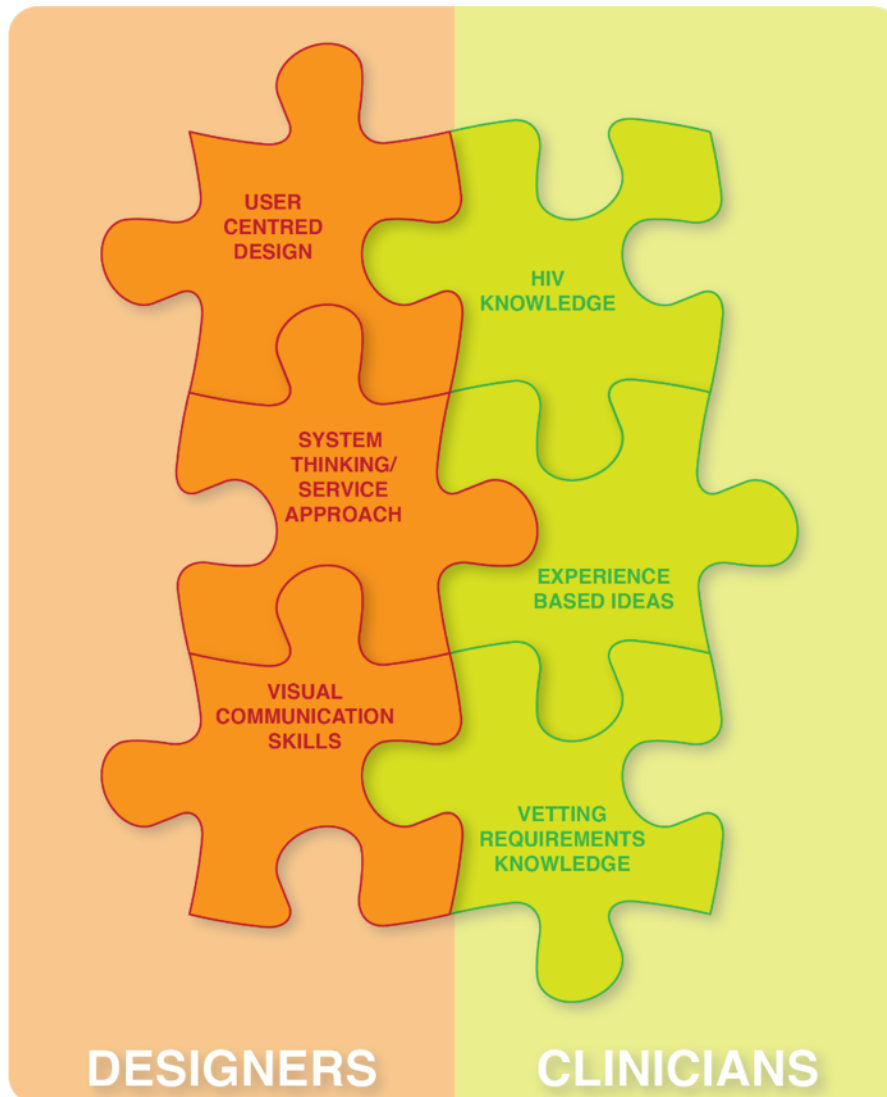


Figure 8. HIV collaborative projects timeline

Conclusions

This research showed how doctors could recognise the usefulness of the design process through the identification of specific design skills and expertise. However doctors' appreciation of the design process as a holistic approach to address issues related to HIV prevention, diagnosis and stigma is still uncertain.

Perhaps this can be explained by the contrasting differences between the scientific approach of medics and the designerly approach of designers.

The medics want a clearly articulated, transparent process that can be held up to scrutiny and examined from beginning to start so that any potential weaknesses or stress points can be eradicated or tested out in advance. Fully knowing the process is essential to them.

In contrast, the designers do not know in advance; they trust their process and the interaction it will produce. They trust –because it has happened many times before – that if they create the conditions, an outcome will emerge that is born from those conditions, but which cannot be known in advance.

This is a most significant difference. The difference in process and knowing/not knowing outcomes. On this point, doctors and designers need to learn to trust each other and share enough to reassure but still give each other space.

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The co-design of a psychosocial intervention for 8-11 years olds with Attention Deficit Hyperactivity Disorder, ADHD Hub

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ABSTRACT ONLY *The co-design of a psychosocial intervention for 8-11 years olds with Attention Deficit Hyperactivity Disorder, "ADHD HubTM" Attention deficit hyperactivity disorder (ADHD) is a long-term neurodevelopmental condition that can affect the individual and their family in a number of domains including education, relationships and self-esteem. It is important that children and young people (CAYP) with ADHD learn about their condition and how to manage it to help minimise ADHD related difficulties. Educating a child about their condition earlier on can enable them to manage it more effectively. Therefore we aimed to design an online platform, "ADHD HubTM", for 8-11 year olds with ADHD to help teach them about their ADHD and how to manage it in a fun and engaging way. ADHD HubTM will cover a number of topics including what ADHD is, ADHD medication, how to explain ADHD to others, managing ADHD at school and home and maintaining friendships. Our initial phase was to utilise a co-design method involving stakeholders (CAYP with ADHD, parents and clinicians) to identify the content and design ADHD HubTM. This was achieved through workshops and communications with stakeholders. We worked with Design Futures (Sheffield based design company) to use information from stakeholders to create an initial prototype of ADHD HubTM . The next phase will involve adopting a user-centered design methodology to conduct workshops to help improve existing prototypes of ADHD HubTM and to create downloadable resources. This is to ensure that children who don't always have Internet access or a device are still able to access and learn from ADHD HubTM . Concurring with Dewey's Experiential Learning Cycle, the downloadable resources will enable the child to learn by providing activities enabling them to reflect on abstract concepts and generalisations. The child will be able to carry out physical activities in order to embed knowledge, on a physical and cognitive level, gained from ADHD HubTM .*

Keywords: ADHD, technology, Dewey's Experiential Learning Cycle

Designing a mobile game to educate and improve healthcare engagement around skinsores in children.

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ABSTRACT *We present the design of a persuasive game to improve healthcare engagement and education in children with skin sores from areas with little access to healthcare, particularly Māori populations in rural communities in New Zealand. Health behaviour issues such as low adherence to treatment regimes impact the success rates of treatments in children with skin sores, particularly in areas with little access to healthcare. Literature suggests that telehealth and game design are viable solutions, as they can be used alongside persuasive strategies to engage children with their healthcare.*

We developed criteria for designing a health game by identifying suitable theories to encourage positive health behaviours. These included flow, simulation and personalization as well as the information, motivation, strategy model to increase engagement. The main criteria are that the game contains an educational component, encourages prolonged use and shows progression through treatment/game.

Methods included interviews with clinicians, children and their families, journey mapping to guide development of suitable art and interactions to fit the criteria and create a functional game demo. This output was tested using the system usability scale and questionnaires adapted for children. The game was assessed against criteria developed over the research period. The output also includes a report on how the participants received the game and the persuasive strategies used within it. This addresses whether the game is usable and enjoyable for the age range and whether engagement and education increase around treatment steps.

Findings from this study discuss how simulation can be used to educate children about their treatments.

Keywords: persuasive strategies, children's healthcare, game design, simulation, education, engagement

Introduction

Skin sores are a common health problem in children (Cole and Gazewood 2007, 879). Untreated skin sores can result in hospitalization, as they can turn into serious skin infections, or lead to blood poisoning (Workbase Education Trust 2012, 2). New Zealand hospital admission rates for children with serious skin infections in 2006 were double those in USA and Australia (Craig et al. 2007, 278-282). Evidence shows that children with certain types of serious skin infection, such as impetigo, may also be at risk of rheumatic fever (Tilyard and Harris 2012, 15), which can lead to rheumatic heart disease (Craig et al. 2007, 274).

Key factors that influence the high rates of skin infections in New Zealand include a lack of knowledge about skin infection (Simpson 2017, 70), access to primary healthcare (Craig et al. 2007, 278-282) and socioeconomic deprivation (O'Sullivan et al. 2012, 47). iMoko is a telehealth programme looking to address some of these issues by placing technology into schools to assess and treat common childhood ailments (Navilluso Medical LTD 2016). However, there is a need to ensure treatment is completed correctly. We partnered with iMoko to develop a game that children can play while following the iMoko programme, to engage and educate around the treatment process.

Treatment for skin infections is highly successful if followed properly, and can include: cleaning wounds, washing hands, covering sores, cutting fingernails and taking antibiotics (Hunt 2004, 40; Ministry of Health 2017). If prescribed, patients need to adhere to their antibiotic medication when treating skin sores until it is finished, even if they appear to be healed (Workbase Education Trust 2012). The highest rates of skin infection are in children age 0-9 (O'Sullivan and Baker 2012, 75). The target age group for this project is children age 5-7, as they are the children most at risk that the iMoko programme can reach.

Studies show the incidence of skin infections requiring hospitalization in New Zealand is higher in Māori and Pacific Island children (Williamson et al. 2013, 924-925; O'Sullivan, Baker, and Zhang 1800). There are multiple possible reasons for this, including a lack of access to healthcare, household crowding and socioeconomic factors (Williamson et al. 2013, 1118). Designing with these factors in mind was valuable to create appropriate healthcare communication, explanations, language and graphics.

Game Design for Healthcare

Serious games are a viable solution to health behaviour issues as they can expose players to content repeatedly, providing endless opportunities to practice skills and see related results of health choices (Lieberman DA 2001, 26). The benefits to the patient can include improvements in adherence, treatment outcome, and the relationship between the physician, parent and patient (Gokhale and Gokhale 2015, 55).

Design can use persuasive strategies as motivators to influence behaviours (Rodríguez Ramírez 2012). Serious games can change behaviour by persuasion and social influence instead of methods such as coercion or deception (Oinas-Kukkonen and Harjumaa 2008, 200).

Different persuasive strategies have varying effects on motivation in different people with varying personality traits (Orji 2017, 1019-1022), therefore tailoring a game to the audience is likely to make it more effective. For this project simulation and personalization strategies were used, as they are positive motivators for most traits and have no negative effect on the other Big Five Personality traits (Orji 2017, 1022-1023). Simulation allows the user to see the effects their actions have, and personalization tailors content and function to users' needs from their characteristics (Orji, Nacke and Di Marco 2017, 1016).

Methods

Aim 1: Design a health game

We interviewed two clinicians who treat children with skin sores on a daily basis from the communities the iMoko programme addresses, mainly rural Māori communities in New Zealand. We also interviewed six children who had gone through skin sores treatment and their parents. We asked them about their overall experience going through the treatment and tried to identify any barriers.

Design criteria were formed from the background research and literature review (Rodríguez Ramírez 2017), and were used as the starting point for the design process and to test the resulting designs. We engaged in an iterative design process to produce design concepts and prototypes, testing them with clinicians and children.

In the initial formation of criteria journey mapping assisted in finding areas where the design of a game could help within the treatment process. This involved mapping out a user's journey with a product from start to finish to find pain points where design could improve the experience (Curedale 2016, 39). It was used again later to show how the gameplay experience fits alongside treatment as the final output was created.

We used thematic analysis (Alhojailan 2012, 40) to construct themes based on the qualitative data gathered from interviews with clinicians, children and their families to form the initial criteria for the design of the paper. We also used thematic analysis to evaluate the results from the observations of children using the game at different iterations of the design.

Aim 2: Test design

It is necessary to test with children as they have different expectations than adults and therefore designing from an older viewpoint could lead to incorrect assumptions (Andersen, Khalid and

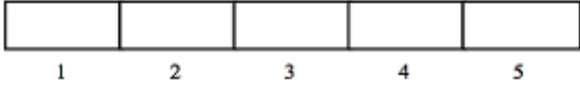
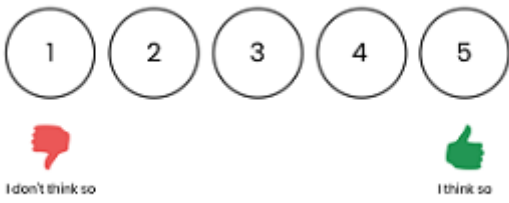
Brooks 2016, 236). Standard user testing methods required adjustment as usability heuristics, like the Standard Usability Scale (Brooke 1996, 4), use language and structure unsuitable for children (Bell 2007, 463), which could affect results. Questions for children should use simple language, be short, and have explanations if necessary (Bell 2007, 463).

The demo of the game was tested with 9 participants between the ages of 5 and 7 at their primary schools. The primary schools were recruited by iMoko, as they represent the demographics of users of their telehealth programme. They are decile 1 (lowest socioeconomic areas in New Zealand) schools in a rural area. A high percentage of the students are Māori. Each participant played through the game, filmed by multiple cameras to capture body language and facial expressions as well as device interactions. We assisted if the participant asked for help or could not continue in the game for more than 15 seconds.

Usability

The Standard Usability Scale (SUS) (Brooke 1996, 4) was adapted to be suitable for children. We tested the SUS through readability scales to assess the reading level. We then simplified the language and ran the readability tests again. The statements were also read out loud to the participants and the scale itself modified to use stickers and visual cues to facilitate children participation.

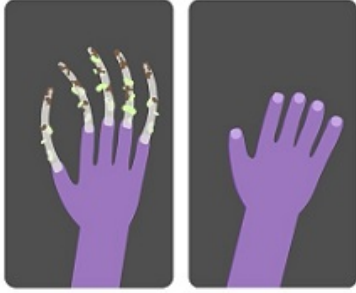
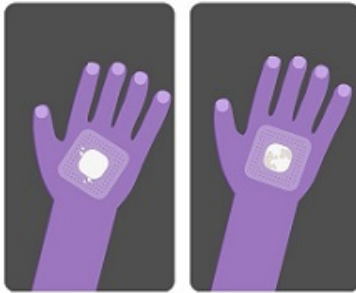
Table 1: Original and adapted SUS comparison

Original SUS	Adapted SUS
<p>Strongly disagree Strongly agree</p>  <p>1 2 3 4 5</p>	 <p>I don't think so I think so</p>
<p>Statement e.g.</p> <p>I think that I would like to use this system frequently</p>	<p>Statement e.g.</p> <p>I think I would like to play this game lots</p>
<p>Readability results:</p> <p>Flesch Reading Ease score: 73.4 (fairly easy to read)</p> <p>Automated Readability Index: 4.3 (8-9 years)</p> <p>The Coleman-Liau Index: 7th grade</p>	<p>Readability results:</p> <p>Flesch Reading Ease score: 107.5 (very, very easy to read)</p> <p>Automated Readability Index: -0.3(3-5 years)</p> <p>The Coleman-Liau Index: 3rd grade</p>

Education

For testing whether the participants had been educated about how to treat their skin sores, we used flashcards and asked the participant what they could tell us about the pictures. In case no answer was given we had prompts to find out if they learnt the basic idea of each minigame.

Table 2: Education testing flashcards and related questions

Flashcards	Open ended question	Prompt 1	Prompt 2
	"What can you tell me about these two pictures?"	"Which picture has nails that won't spread germs?"	"What can be done to stop the germs from spreading from this one?"
		"Which picture has a dressing that needs changing?"	"Why does it need changing?"

Engagement

We used observation (Curedale 2016, 110) for testing engagement, looking for body language and verbal response. There was also a question linked to engagement within the adapted SUS that addressed how often the participant would like to play. At the end of the session the participant was asked if they would like to play the game again to see whether it was engaging enough to make the participant want a second turn.

Results

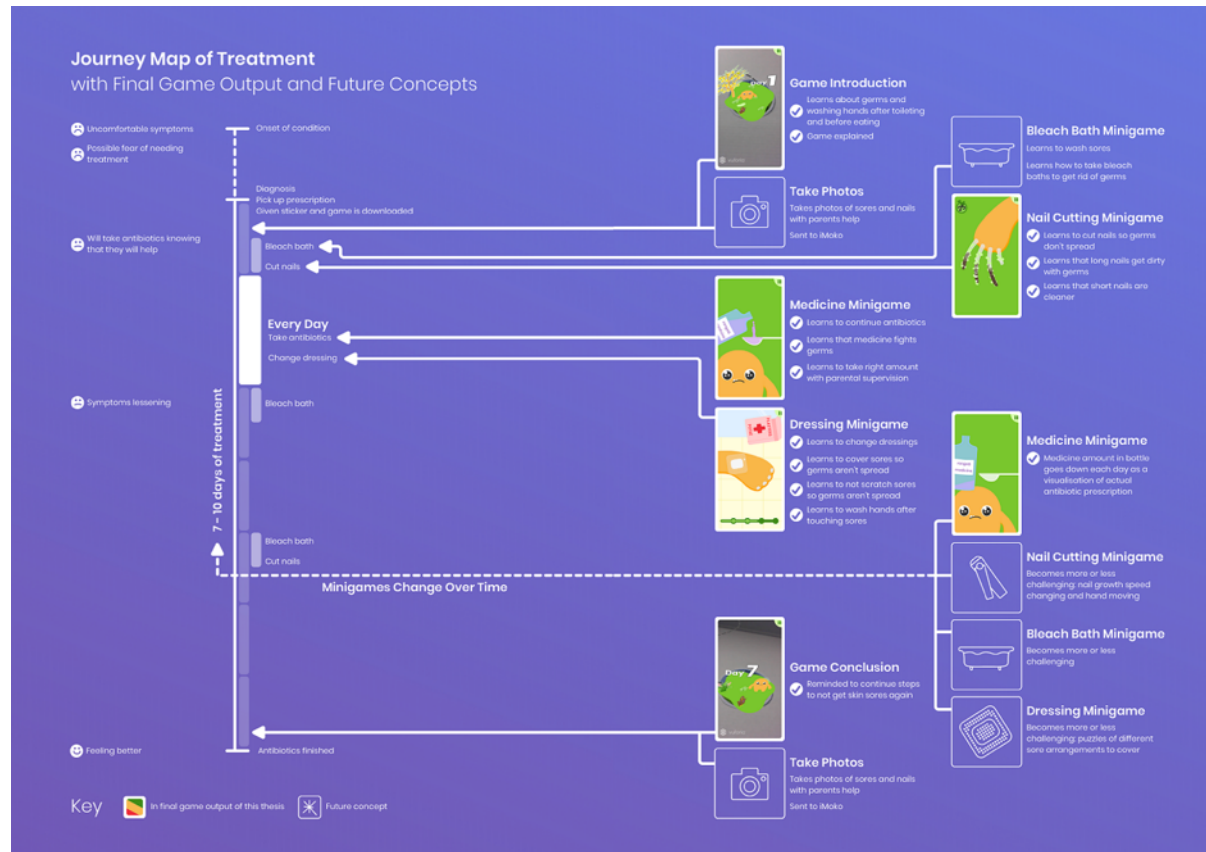


Figure 1: Journey Map of Treatment with Game Structure

Criteria

The following criteria were constructed based on a thematic analysis of the interviews with clinicians, children, their families and reviews of literature and design precedents.

1. The game should provide education around why treatment is necessary as well as how to complete treatment steps.
2. The game should remind the player to complete each of their treatment steps on the required days.
3. If the player is prescribed medicine, the game should remind them to take the correct dose with parent/caregiver assistance.
4. Healthcare communication should be personalized and directed to the child with age appropriate explanations, language and graphics.
5. The game should remind the user to continue treatment even once they feel and appear to be better, along with an explanation of why this is necessary.
6. The game should provide clear feedback to actions, including praise.
7. The game should become more or less challenging over time to adapt to the player's skill.
8. The game should involve simulation of the treatment to educate children.

Game Structure

Findings from the thematic analysis of interviews with children identified that there is stigma around skin sores and they prefer not to be related to the condition. This led to the concept of the child helping a doctor (a kiwi, which is the national icon of New Zealand) to care for a creature that needs treatment, rather than direct the treatment towards the child. The creature is based on drawings produced by the children in the interviews. Each day there are minigames that teach the child parts of the treatment, including clipping fingernails, baths, washing hands, keeping sores and dressings clean, taking full dose of antibiotics when necessary. For instance, a nail cutting minigame was designed to simulate nails growing long and getting covered in germs. The player could see the effects of the treatment step of getting rid of the germs by swiping a finger on the screen to cut the nails.

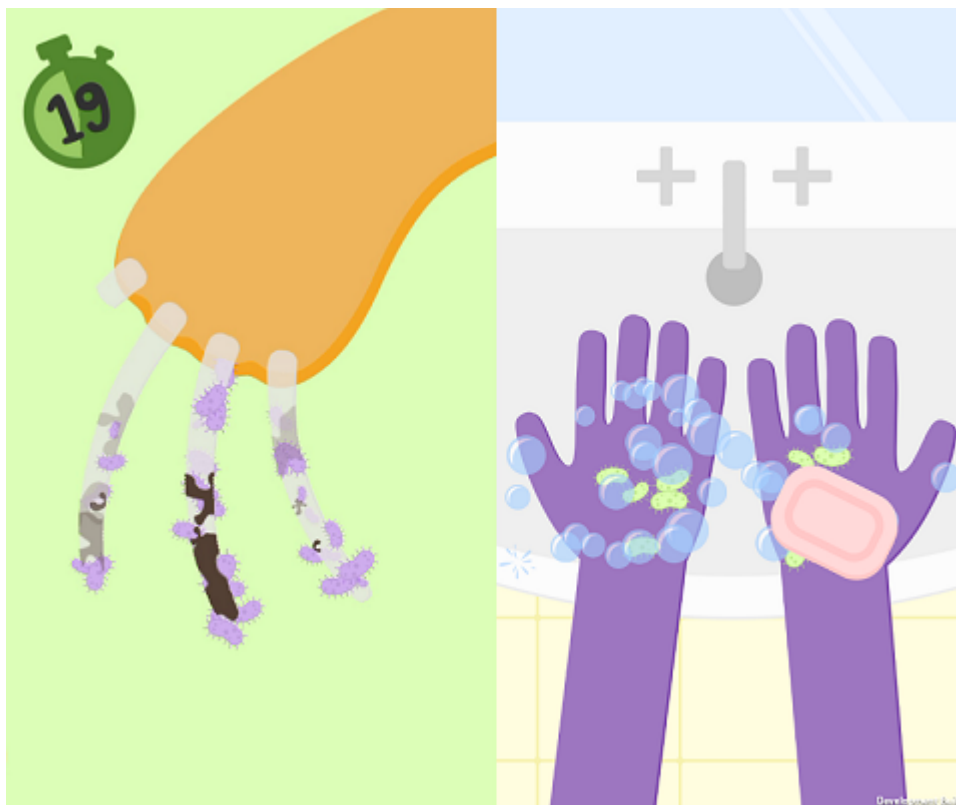


Figure 2: Screenshots of minigames

Augmented Reality

Augmented reality (AR) is implemented within the game to create a link between the game and the users' treatment. A physical marker is used to trigger the AR and make the game map display of the all the days of treatment.



Figure 3: Augmented reality game map

This marker was designed to be placed on the treatment kit so that the user has to find every time they want to play the game and be reminded to take their medicine and complete treatment steps. The game map shows the characters in AR on the current day and plays an introduction explaining the treatment step before each minigame begins.

Testing Results

Figure 4 shows a radar chart of the average and median responses for each SUS statement. Most participants did think that they would want to play the game often and that they could play it well. Interestingly the results show that most participants found the game a suitable level of difficulty yet did not think all children their age could play it. Most participants thought that they could play the game without help.

The first day of testing returned a median SUS score of 65. Between the two days of testing some usability issues were fixed within the game, particularly around participants not swiping more than once to play the nail cutting game properly. This issue was fixed by voiceover prompts to swipe the nails again they grew too long. This appeared to have a positive impact on the median SUS score which rose to 82.5.



Figure 4: Responses to SUS

The analysis of the education testing found that simulation was a successful strategy to teach children how to treat their skin sores. Most participants pointed out that the long nails were dirty with germs. Some participants gave no answer to how to get rid of the germs others said to wash or wipe the germs off instead of cutting the nails. Regarding the dressings, most participants said one plaster was dirty but sometimes pointed at the wrong graphic or gave no answer. When asked why it needs changing, the majority answered because it was dirty.

The majority of the participants agreed with the SUS statement related to engagement that asked whether the participant would like to play the game. When asked if the participants wanted to play the demo again at the end of the session the majority said yes.

The SUS was adjusted as rating negative statements highly to agree with the statement was confusing participants. Each individual statement was explained how it related with the scale and two very similar questions were merged. The first day of testing returned an average SUS score of 56.6. Between the two days of testing usability issues were fixed within the game, particularly around prompting to cut the nails. This appeared to have a positive impact on the average SUS

score which rose to 79.16. The low participant number could mean that this was just by chance, however both times the usability score was passing. Testing process could be improved further by refining the SUS questions to gain more usable answers from child participants.

Discussion and Conclusions

The design output of the game demo meets most of the criteria. Healthcare communication is personalized and directed to the child using suitable language and graphics for the age range to explain treatment. Every completed simulated treatment step minigame gives the player praise and provides an explanation of how their actions help complete the treatment. Having individual treatment steps as minigames makes the game modular for different regimes and provides an opportunity for minigames to adjust to the players' skill.

Future research allows the criteria to be used to build health games for other common childhood ailments as well the opportunity for a clinical trial of the game. This study showed that it is valuable to consider simulation as an engaging form of education around healthcare treatment steps. This research will be applied in a real-world content as findings will assist in building the demo of the game into a fully functional output to be delivered via the iMoko programme. Implications for game design aiming to address healthcare in rural communities include how children can be engaged and educated around their treatments through simulation without having to continually see a clinician in person.

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Developing Future Capacity: Exposing Healthcare Organizations to Design through a University-Based Health Design Lab

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ABSTRACT *The Health Design Lab (HDL) is a research and design centre based out of Emily Carr University of Art + Design in Vancouver, Canada. The lab seeks to connect undergraduate and graduate design students and faculty with industry and community partners to collaboratively apply human-centred design approaches to the improvement of health products, services and systems.*

The use of design methods and design thinking within healthcare organizations within Vancouver, Canada is limited. Further, when organizations do begin to gain awareness of approaches such as 'design thinking' and 'co-design' they often do not realize the value of designers in the application of these approaches and methods. Therefore, HDL seeks to introduce healthcare organizations to the role of designers and design approaches within their context, in order to build the capacity of healthcare organizations, as well as future designers emerging out of undergraduate and graduate design programs.

HDL collaborates with healthcare organizations through two key models: course-based projects & funded team-based projects. This paper describes and discusses these two models for collaboration and highlights some of the ways in which we are seeing this strategy benefit healthcare organizations and design students.

Projects referenced in this paper include: a co-design project between residents in a long-term care facility and a class of undergraduate students, a hand hygiene campaign, the design of a new lighting system for a long-term care facility, community-engagement work to support the design of a new hospital and the design of an app in collaboration with a clinical team. These projects act as case studies to explore ways in which a design institution may foster a greater shared understanding of the role of design in healthcare, in an attempt to ultimately establish greater opportunities for designers within this context to improve patient care.

Keywords: human centred design, healthcare, design students, design lab, design approaches

Introduction

‘...it is true to say that whilst design and health have always been connected we are entering a new era, new territory, where many elements have yet to be fully resolved, where understanding needs to be built and critical perspectives offered.’ (Chamberlain and Craig 2017)

There is growing support for, and increasing recognition of, the role of design to improve health and healthcare products and services. An increasing aging population, the rise of chronic diseases, changing roles of patients and new technological advances are creating vast opportunities for healthcare advancement (Cottam and Leadbeater 2004). In innovative healthcare systems we are seeing an expanding role for designers in creating enabling ecosystems for change (Manzini 2015), however, while the relationship between health and design is growing or rather, coming together, there still remains a large gap in the understanding and application of design within healthcare contexts. As Chamberlain and Craig (2017), ‘building an understanding of our different but complimentary approaches in design and health is vital’. But how do we do that?

While a variety of approaches and strategies are necessary to further advance collaboration between health and design, this paper proposes that university-based health design labs are one way in which design can be effectively introduced to healthcare organizations, and in turn, healthcare challenges and contexts can be introduced to emerging designers.

The use of design methods and design thinking within healthcare organizations within Vancouver, Canada is limited. Further, when organizations do begin to gain awareness of approaches such as ‘design thinking’ and ‘co-design’ they often do not realize the value of designers in the application of these approaches and methods. With these challenges in mind, the Health Design Lab (HDL) at Emily Carr University of Art + Design in Vancouver, Canada aims to bridge this gap in understanding. HDL is a research and design centre based out of a public art and design university that connects undergraduate and graduate design students and faculty with industry and community partners to collaboratively apply human-centred design approaches to the improvement of health products, services and systems. One of the goals of the lab is to build the capacity of healthcare organizations to better understand and utilize design, as well as to build the capacity of students to emerge as designers with the skillset necessary to work in health and healthcare contexts.

Health & Design Labs

Many design labs focused on health and well-being currently exist, and continue to emerge, including several in the US, Europe, and New Zealand. The growth of these types of labs demonstrates a growing understanding of the role designers can play in addressing some of our most complex and rapidly shifting challenges in health (Chamberlain and Craig 2017; Bowen et al. 2013).

Many of these labs are connected to single hospitals or health organizations and most are run by groups of researchers and/or professional designers. The Health Design Lab at Emily Carr University, rather than being situated within a specific health organization, is based in a University context and collaborates with a wide range of partners including several different health authorities and hospitals, non-profits organizations and local start-ups and industry partners. As such, HDL tackles a range of health challenges in a range of contexts. One of the unique aspects of HDL is its relationship to the undergraduate and graduate design programs at Emily Carr University. Health design is not a specific stream, but rather, community-based health design projects are placed within a range of courses as part of curriculum, and students across various streams of undergraduate and graduate design are hired as Research Assistants to work in the lab. The lab is in essence, 'student-powered'.

Capacity Building

Over the past six years as HDL has grown, we have explored a variety of partnerships and methods for collaborations, realizing that one of the key functions of the lab may be its ability to expose health organizations to the possibilities and benefits of collaboration with designers. The lab currently collaborates with healthcare organizations through two key models: funded team-based projects & course-based projects. This paper describes these two models for collaboration and highlights some of the ways in which we are seeing this strategy benefit healthcare organizations and design students.

While the lab collaborates with a range of partners including local start-ups and industry partners, this paper focuses on highlighting our collaborations with local public hospitals and health authorities.

Team-Based Projects

One of the key ways in which HDL collaborates with local hospitals and health authorities is through funded team-based projects. In these projects, a team of students from undergraduate or graduate design programs are hired as Research Assistants to work on a project under the guidance of the HDL Director or an associated faculty member. In this case, the projects act as valuable work experience for students in a real-world context that balances innovation with practical limitations of our health system. These projects range from the design of products or communication tools to the facilitation of co-design workshops and service design projects.

Example 1: IlluminAid

In 2015-2016, a team of students were hired as Research Assistants to collaborate with a local residential care facility to explore ways in which the clinical environment could be more home-like. Emerging from this six-month project was a series of co-designed ideas and early stage

prototypes. One key observation was the need for improved lighting in the resident rooms at night to reduce sleep disturbances and falls risks. Through a human-centred design approach, overnight ethnographic observations and onsite user testing, HDL conceptualized a motion-sensor lighting solution for existing facilities to meet the needs of residents and staff. To address the challenges of implementation and barriers that come with custom manufacturing and safety requirements for new products in a clinical context, the team was able to identify an existing market solution that could be adapted to meet all of the necessary design requirements. In this case, the lab played a key role in expanding the capacity and capability of the health organization to solve a challenge, while exposing them to the role of designers and design methods. The organization has since continued to hire one of our research assistants, now an alumnus, to complete several other design projects within their facility.

Example 2: Sleep-Wake Behaviours App

While some HDL projects begin with an exploratory, problem-finding phase, others are clearly defined by a healthcare professional who is looking for design support on a project in progress. For example, in 2015 we were approached by a physician and sleep specialist who was looking for help to design an app to help parents better track their children's sleep and wake behaviours, to ultimately allow physicians to better treat sleep disorders for children with neurodevelopmental challenges. In this case, a small team of three students and two faculty worked collaboratively with the physician and his clinical team, to design a family-centred app. In this project we observed that although the physician was interested in creating an app, his understanding of design was quite limited, thus a major aspect of this project was the education of the clinical team to design methods and processes, as well as a focus on shifting the design of the app from the clinician's original vision, to one that more closely aligned with parent needs through a participatory design approach. As evidence of capacity building, two years later this clinician has continued to hire Emily Carr University design students to support his research, and one of the students who worked on the original app design now works for a local digital health company.



Figure 1: HDL team reviews data collected in a participatory design workshop to inform the design of an app

Example 3: Front Entrance Experience

Some of the projects in HDL focus on the design of tangible product-based outcomes, while others focus on the use of designers in leading community-engagement initiatives, utilizing co-design methods. As health authorities try to become more patient-centred, there is a growing focus on patient involvement. This however, often ends up looking like the professionalization of patients as patient advisors and members of committees. HDL seeks to advocate for the use of co-design and participatory design methods as a strategy for patient and community engagement. We recently completed a project with a local hospital that is in the process of designing a new replacement hospital. In order to support their community-engagement work, HDL was hired to lead a series of co-design workshops to generate a series of insights and recommendations for the design of their new front entrance experience. In this case, the lab played a key role in expanding the capacity of the relatively small redevelopment team, enabling a deep dive into a critical space within the new facility. This project resulted in a rich collection of community and patient insights which will be passed on to the future architects. As a first foray into the role of healthcare redevelopment for the lab, this is an area with great potential for design students to contribute new perspectives and ideas and act as facilitators for co-design and community engagement.



Figure 2: HDL team facilitating a participatory design workshop to inform the front entrance experience of a new hospital

Funded team-based projects allow HDL to create professional work opportunities and immersive learning experiences for students, while expanding the capacity of healthcare professionals and organizations to address challenges with limited resources. These projects do however require funding to support the design team, in an effort to ensure that we are accurately valuing design and establishing a framework of fee-for-service work that will benefit future designers entering this industry.

Course-Based Projects

In addition to the team-based project model, HDL also leverages the capacity of the University by providing opportunities for course-based projects. These are projects in collaboration with community partners that are embedded as assignments into existing courses in one of three undergraduate design programs: communication, interaction or industrial design. From a University and student perspective, this model allows us to link faculty research and community initiatives directly to curriculum and expand our pedagogical model to provide immersive, experiential learning environments for students. For health organizations these projects allow them to gain an entry point into collaboration with designers and this context is often well-suited to early-stage idea generation.

Example 1: Hand Hygiene Campaign

In 2016, one of our local health authorities was interested in producing a new hand hygiene campaign for their facilities, directed at patients and visitors. We embedded an 8-week assignment into a communication design course, in which students were asked to generate and pitch a series

of hand-hygiene campaign concepts to a team from the health authority's Patient Safety and Quality Department. This project included on-site tours, observations, and a co-design workshop led by students with various healthcare professionals. This gave students an opportunity to explore and test various design research methods with real users and to practice pitching design concepts. Following the end of this 8-week assignment, the health authority project team selected one design team's concept for implementation. These students were then hired as Research Assistants to refine the concept and create production files for the client. This provided strong professional experience for the students and extended the capacity of the health authority's communication department. The health authority project leader provided the following feedback: 'working with the students allows us to see our challenges and solutions in new, creative, insightful, and often unexpected ways'. Within the three months, the campaign was rolled-out in healthcare facilities across British Columbia.



Figure 3: Final hand hygiene campaign installed in hospital elevator

Example 2: Zeitgeist

In many HDL projects, we are responsive to the requests of partners in relation to needs and potential solutions which they have identified. One of the goals of the lab however, is to not only respond to requests, but also to push out ideas which have emerged from our own insights into design opportunities within the health system. The course-based context creates a space where we can pilot new ideas in order to bring external partners on board.

Through several past projects within residential care facilities, HDL became aware of the importance of storytelling for seniors with dementia. With this need in mind, and inspired by the work of designer Carolyn Kerchof (2015), we identified an opportunity to integrate a storytelling co-design project into a communication design course which would pair students with residents in teams to create mini-publications of resident stories. Initiated by the HDL Director and an Assistant Professor in communication design, we searched for a care home that would be interested in collaborating with us on this pilot project. Through a partnership with a local residential care facility and an enthusiastic Recreation Therapist, we were able to pilot an 8-week project, which involved 6 visits at the care facility for students and residents to collaboratively co-write and co-design a set of publications. This mutually beneficial project created a unique learning context for our students to apply and practice their design research, storytelling and communication design skills through direct interaction with seniors. Simultaneously, this project extended the capacity of the care home to provide therapeutic recreation and social activities to its residents, a critically under-served need. The successful collaboration sparked the interest of staff within the facility as well as the health authority in which it is located, and we are now looking to further expand this project.



Figure 4: Students and residents collaborate to co-design publications

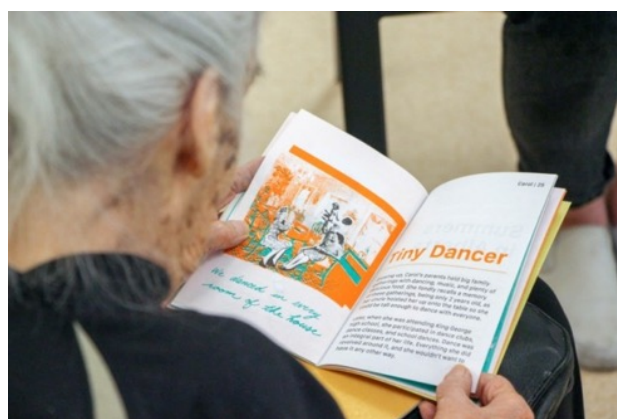


Figure 5: Resident reading the final publication featuring her story

Conclusion

While several successful collaborations have been highlighted here, there are certainly still struggles and challenges with these types of projects and engagements. The biggest hurdle in many cases remains around the communication and understanding of what design is, and how design methods can align and enhance current healthcare initiatives. With each project however we get a little bit better at introducing design, and we provide opportunities for students to develop these communication skills as well. We have come to realize that there is a critical opportunity for the lab to advocate for the role of designers.

From a student perspective, we have observed that the lab helps to expose student to healthcare contexts as opportunities for design, and many choose to seek work in these areas post-graduation. Further, the lab provides experiential learning opportunities for how to navigate complex social challenges as a designer, and how to advocate for one's role and involvement in these types of systems where the adoption and integration of design is emergent.

From a health system perspective, we have observed that through collaborations with the lab we have started to expose the healthcare system, practitioners, and health researchers to the role that design can play in improving health systems and products. For many of our partners, our projects are their first interaction and exposure to design. As a University, we have the benefit of creating this introduction through our students, in such a way that reduces barriers, and provides a lower-cost way to introduce design at a small scale, in order to educate, and extend the capacity of healthcare organizations and their existing staff teams.

The project examples presented here are offered as case studies, to explore ways in which design institutions may foster a greater shared understanding of the role of design in healthcare, in an attempt to ultimately establish greater opportunities for designers within this context, to improve the health and well-being of our communities.

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Designing person centred products for people living with dementia

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ABSTRACT Current approaches to dementia care emphasize the importance of person-centred approaches to care that focus not only on health, but also on psychosocial aspects, and adaptation of the environment to support the needs of the person with dementia. Person-centred care involves a detailed understanding of the person living with dementia and their experience: their life history, achievements, interests, preferences and relationships, and using this information, where possible, to support respectful and collaborative relationships between the person, their family and carers. Knowing a person with dementia better is demonstrated to improve professional carers' attitudes towards, and care provided to the person. However, staff in care settings are often forced to focus on interventions to manage problematic or challenging behaviours, which can leave very little time for interventions that promote self-esteem, awareness of personal identity, warm relationships, and positive behaviours. This paper explores the role of creative practice to support innovative person-centred approaches to dementia care. We describe a series of design-led interventions that are part of a programme of research aimed at improving wellbeing and personhood of people living with dementia. The projects described could be used to support care both in a specialized care setting and in the community.

Keywords: creative practice; co-design; person centred care; dementia

Introduction

There are an estimated 50,000 people with dementia in New Zealand costing around \$1 billion each year (Alzheimers New Zealand 2012). In the absence of a cure, the Ministry of Health set an overarching direction for dementia care and support in the New Zealand Framework for Dementia Care (Ministry of Health 2013). The framework focuses on improving the wellbeing and quality of life for people with dementia, their carers and families through providing ‘appropriate, person centred, and high quality proactive and coordinated services and support’ (Ministry of Health 2011). As their cognitive abilities deteriorate people with dementia may become socially isolated, ignored, bored, frustrated, and may display changes in behaviour (Ministry of Health 2011). Cognitive impairment and the person’s response to their situation affect how these individuals are perceived and responded to by others (Kitwood 1997).

Current approaches to dementia care emphasise the importance of person centred approaches to care planning and adaptation of the environment to support the needs of the person with dementia. Person-centred models of care seek to use a detailed understanding of the person’s current experience, their life history, achievements, relationships and preferences, to support carer-resident relationships which promote respect and individualised care (Chenoweth et al. 2009). Knowing a person with dementia better is demonstrated to improve professional carers’ attitudes towards, and care provided to the person (Reichman et al. 2004). This results in increased confidence in caregivers’ decision-making and care planning for the person in their care (Burgener, Shimer, and Murrell 1993). Preserving a person with dementia’s identity helps improve their wellbeing (Clarke, Jane Hanson, and Ross 2003).

This paper describes three projects from a programme of research aimed at improving wellbeing and personhood of people living with dementia through interventions that engage them in activities that help to better understanding what matters to them.

Wayfinding in an acute setting.

Poor wayfinding results in stress and anxiety (Mollerup 2013). Difficulties in way-finding are common for people with dementia and are exacerbated by a move to an unfamiliar environment. So-called ‘wandering’ rather than aimless ambulation may in fact be a communication that the person is trying to find a familiar space, their bedroom, or privacy. This project explored wayfinding in a secure inpatient older adult mental health facility in a central city Hospital. Three quarters of service users have some cognitive impairment, with around half having a diagnosed dementia, and other service users having conditions such as severe depression, bipolar disorder or schizophrenia. About half of service users are subject to mental health act compulsory assessment and at the time of admission many are in a state of significant psychological distress and are often reluctant to stay. There is a considerable through-put of service users, with many experiencing disorientation. Consistent with many hospital facilities, the rooms are similar with multiple rooms off a corridor, and service users often find it difficult find their way back to their rooms, even when

their name is on the door (Figure 1). Clinicians and designers used co design to explore the patient door sign problem. Due to the relatively small scale of the project and the cognitive and consent challenges associated with the patient user group, they were not involved in the design process.



Figure 1: Existing room signage in the facility

Simple concepts were developed about activities that an occupational therapist might use to engage service users to explore what they would like as ‘their’ sign. Due to high service user turnover, and busyness of staff a templated approach was required for a customizable solution. The project team speculated on what service users might consider as meaningful images, images of special personal interests, images that symbolize values that were important to them and cultural images. It was found that many service users wanted to find or create their own image.



Figure 2: Concepts and prototypes developed during the project; early frame ideas (top), template (bottom left) and a more resolved frame prototype.

The frame was developed so that the image/sign could be easily slid in and out, as new service users arrived, or wanted to change or modify their sign (Figures 2 and 3). There were several important design criteria that were specific to the context. These included, 'glass' that was unable to be broken and used to cut, the use of quality materials to contrast the clinical feel of the environment, the frame needed to be removed from the wall easily, and the A4 sign able to be easily replaced without taking the frame apart (e.g. removing the back). It was also important that the easy removal of the A4 sign was disguised to service users, as their condition means they often pick and pull at things. Also, it was felt important that the frame resembled a permanent and treasured artefact as might be expected of a picture frame at home. A working team of designers made and assembled 24 frames for installation throughout the facility (Figure 4).



Figure 3: Prototype testing how the 'template' sign could be easily inserted into the frame.

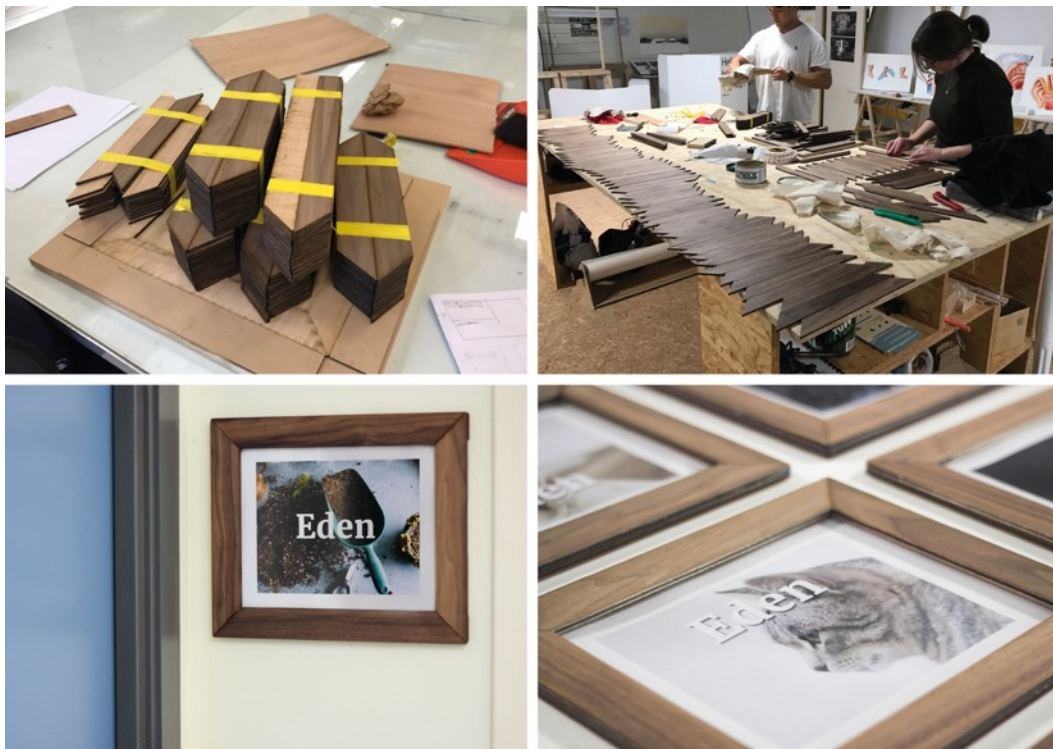


Figure 4: Final frames were cut using a laser cutter (top) and assembled (top right); the final sign (bottom left and right)

Through the collaborative design process, it was identified that engaging service users in the process of making of personalized signs aligns with an existing Occupational Therapy process of the Canadian Practice Process Framework (CPPF) (Townsend and Polatajko 2007). An occupational therapist normally completes an initial interview with a new service user around their usual roles and routines. This person centred discussion often leads to the person identifying what is most important to them. There is potential for the sign 'making' to be used to help guide interactions with service users when they first arrive on the ward. Using the stages 'enter/initiate', 'set the stage' and 'assess/evaluate' from the framework occupational therapists can gather information by

aligning the wayfinding frame with the pre-existing process. This means the sign 'making' process will fit into the initiation, rapport building and assessment phase of these initial occupational therapist/service user interactions.

Simulation/sensory modulation (hospital and community)

Up to 90% of people living with dementia often experience depression, agitation and anxiety over the course of their illness (Cerejeira, Lagarto, and Mukaetova-Ladinska 2012). As their cognitive abilities deteriorate and their ability to communicate their needs becomes limited, persons with dementia become socially isolated, ignored, bored, frustrated, distressed, and may display changes in behaviour (Jakob and Collier 2017). Additionally, older people experience reduced acuity of vision, hearing, taste and smell which puts them at risk of sensory deprivation (Haigh and Mytton 2016). The cognitive and behavioural changes associated with dementia, together with lack of sensory-enriching experiences and appropriate activity can be frightening for the person and their carers, and adversely affect the overall quality of life of both persons with dementia and caregivers (Feast et al. 2016). Consequently, these changes often act as a trigger for admission to institutional care (Burns et al. 2002).

Sensory interventions aim to provide pleasurable sensory experiences to stimulate the primary senses without the need for intellectual activity in an atmosphere of trust and relaxation (Burns, Cox, and Plant 2000). Stimuli used for this purpose are non-sequential, experienced moment by moment without relying on short-term memory to link them to previous events (Baker et al. 2001). Consequently, it is one of the few approaches suitable for reaching persons with severe or very severe dementia whose possibilities for verbal communication are limited (Burns, Cox, and Plant 2000). Sensory experiences can produce feelings of pleasure through triggering memories about positively experienced emotions (Treadaway and Kenning 2016).

Multisensory environments can be costly to set up, and they often end up being unused due to lack of time, safety issues, poor design, and lack of the motivation, skills, and knowledge by professional carers to facilitate the use of the multisensory space (Jakob and Collier 2017). Relatives are usually not involved in using them (Jakob and Collier 2017), and they are not easily replicated in a home setting. Further, nature-based elements are currently missing in most multisensory environments (Jakob and Collier 2017). Exposure to nature stimuli may trigger the recall of early experiences of nature which can in turn provide clarity and pleasure for the person with dementia (Kaplan and Kaplan 1989). To be able to achieve this without the risk of overstimulation, users of the environment need to be given more control over their experience than is currently provided (Jakob and Collier 2017).

The project team identified the need for a novel, cheaper, and mobile sensory-based solution to engage persons with dementia that can be readily accessible so people can use it when and as needed. The resulting 'sense' concept was developed as a simple UX based interactive web

resource (Figures 5 & 6) that contains a range of calming and stimulating nature-based videos that range from real life to abstract.

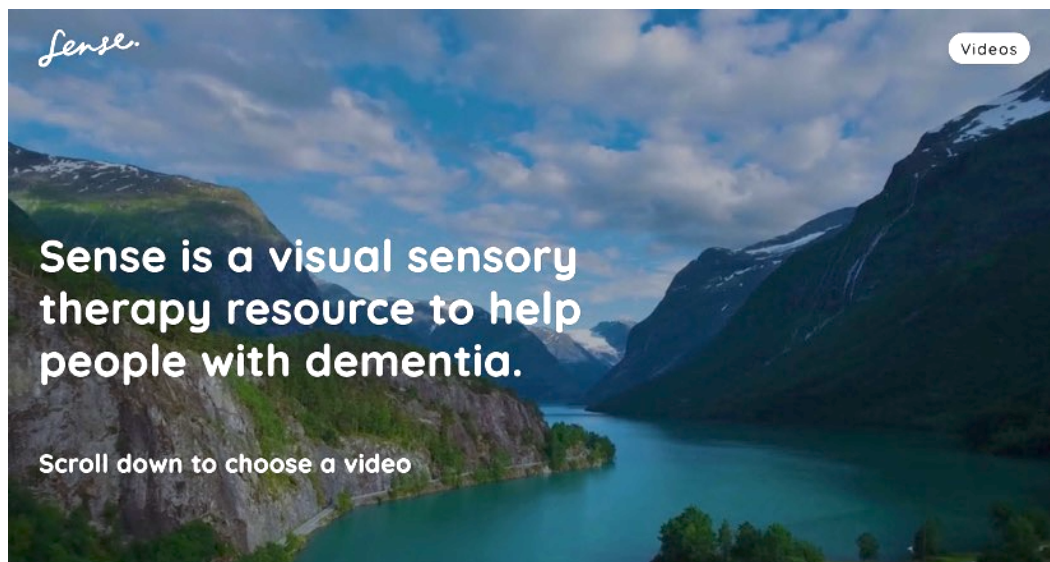


Figure 5: Landing page for Sense website

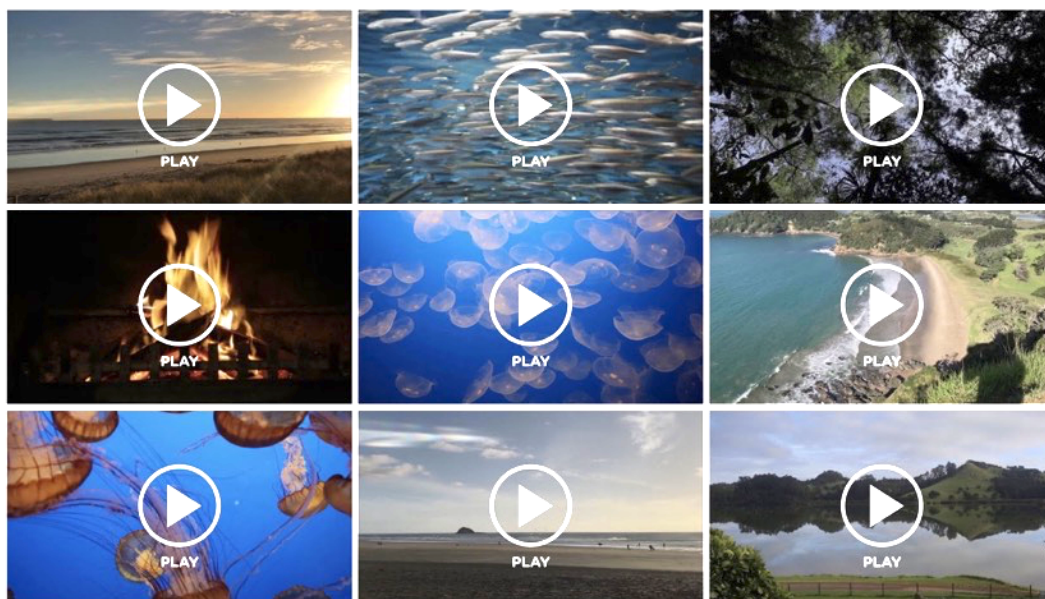


Figure 6: Video menu for Sense website

Communicating with people living with dementia

The loss of memory doesn't necessarily mean loss of identity (Cohen-Mansfield et al. 2015). Not being able to remember can sometimes make it hard for family members or friends to connect to their loved ones. It can be difficult for families and friends to adapt to changes in a person living

with dementia, and to help them live with dignity. While there is a plethora of information on the internet and in books about what caregivers need to know about dementia, it is often overwhelming or difficult to digest by families and friends. This design led project explored how to communicate with someone with dementia. The project team created a card set with practical tips on how to communicate with someone with dementia. While a person with severe dementia may not be able to recognise faces, they can still connect feelings to the person in front of them. Therefore, it is important to help people living with dementia feel good and appreciated through how we talk and interact with them. As such, what we say may not be as important as how we say it and how we act (body language). The design proposal has been kept as simple as possible, with added some colour and humour (Figure 7). In contrast to already existing information texts, the cards are supposed to deliver tips in a fun and easy to understand way. Many cards give general tips on what to do to have a positive and respectful conversation. Those tips could be applied in a conversation with anyone, affected by dementia or not. This shows that people affected by dementia are still people with feelings and don't have to be treated in any other way. The abstract illustrations intend to communicate different emotions and to help families and caregivers remember the content.



Figure 7: Communicating with someone with dementia card deck (R. Kemnitz).

Discussion

In conventional practice in New Zealand caregivers often focus on interventions to manage problematic or challenging behaviours (especially in in acute mental health settings), and may neglect interventions that promote self-esteem, awareness of personal identity, warm

relationships, and positive behaviours (Moyle et al. 2008). Although healthcare staff involved with residents in acute and long term settings routinely collect information necessary to address professional needs, they seldom attempt to compile this information to form a complete picture of a resident's life experiences, values, and identity (Reichman et al. 2004). Personal information collected may not be stored in a way that meaningfully influences care. When older adults with advanced dementia or mental illness are cared for by staff that do not know the individual's history service users face the risk that their individual concerns, moods, behaviours, and background will be discounted (Palmer 2013).

Acknowledging and respecting individual's feelings, needs, and values is central to person-centred practice (Dewing 2002). Telling and listening is a way of creating a common understanding of the person's life and illness experience. Devoting time and interest to listen to an older person's life story in itself may contribute to their calmness, confidence, and wellbeing in a psychogeriatric setting (Edvardsson and Nordvall 2008). This research will address the deficits in the psychosocial care of older adults with dementia and/or mental illness in the acute inpatient setting by exploring how creative methods may be used to engage staff, service users and their families in the co-creation and use of the patient's life story resource as an important part of a therapeutic process.

It is anticipated that the outcomes of these project and subsequent research will support professional and family carers in providing high quality personalised care to older people in an acute psychogeriatric setting by enabling them to understand in more detail the person's past, relationships, their unique needs and interests. It is hoped that through small scale person centred care interventions, such as described here, and design and creative practices can help facilitate a culture change within and beyond acute inpatient psychogeriatric settings and will also be applicable in home and day care, or long-term care settings.

Acknowledgements

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Design model for health behaviour change

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ABSTRACT *A conceptual framework is proposed that addresses sub- and preconscious aspects of design features that might affect health related patterns of behaviour. Building onto Schwarzer's Health Action Process Approach (HAPA; Schwarzer 2004) this model attempts to bridge the gap between design and health psychology. Applying methods and principles from consumer research (e.g. priming) the design model for health behaviour change (DMHBC) is proposed to focus on established concepts and transfer these to the scientific area of design research for health and well-being.*

Studies from fields such as consumer research or neuromarketing show that design features can affect various aspects of social behaviour and judgment (e.g. Kay et al. 2004; Lockton et al. 2010). This applies in particular to the bodily perceptions that design elements can convey (Lobel 2014). In this regard, design features can act as primes and even placebos (Rehn and Schuster 2017) affecting emotional, cognitive and behavioural outcomes. This offers potential for changing health behaviour by addressing mental concepts such as self-efficacy, outcome expectancies and risk perception, which are according to HAPA (Schwarzer 2004) significant elements of the pre-intentional motivation phase and key aspects of a successful health behaviour change process.

Additionally to these pre-intentional influences, design features can as well act as situative barriers and opportunities that affect the post-intentional volition phase. Using knowledge from fields such as universal design (Erlandson 2008) and behavioural economics (e.g. Thaler and Sunstein 2011) design can play a key role in supporting the maintenance of positive health behaviours.

This article introduces the DMHBC and illustrates its chances and limitations as a link between transdisciplinary knowledge and design problems. Case studies support the use of the DMHBC as a conceptual design framework. Further research is needed to analyze the effect of various design elements on particular mental concepts such as self-efficacy.

Keywords: Design research, health behaviour, priming, self-efficacy, health design, psychosocially supportive design, salutogenic design, design methods, evidence-based design, prevention

Design methodology and health behaviour

In many cases design as a practice is commonly associated with creative unplanned processes and the application of chaos and chance as a tool to create new and innovative concepts. However, both design and design research increasingly follow up a tendency of the seventies (see Rittel 1973; Cross and Roy 1975) and make use of theoretical models and structured methodologies in order to conduct a planned design process (e.g. Kumar 2013; Hamilton 2003; Rehn 2017). Most of these methods and models aim at creating concepts, products or systems that suit a certain briefing or have a high likelihood of financial success on the market.

Paradoxically, when it comes to analysing or predicting the effects certain design concepts might have on the behaviour of users or identifying aspects that promote a certain behaviour, fields such as marketing and economics (e.g. Bloch 1995; Bittner 1992; Lobel 2014) as well as social psychology (e.g. de Kort et al. 2008) offer a much broader scope. Only view exclusions in design and architectural research focus on behavioural effects as a goal of design interventions (Lockton et al. 2010; Fogg 2003; Tromp et al. 2011; Zimring et al. 2005), while others still include behavioural dimensions, but rather as a side effect that should be controlled in order to reduce risk (e.g. Norman 1988).

Health behaviour as a key concept in health promotion

With regards to health and wellbeing the concept of health behaviour is of particular importance as Kasl and Cobb describe it in their seminal paper: 'Health behaviour is any activity undertaken by a person believing himself to be healthy, for the purpose of preventing disease or detecting it in an asymptomatic stage' (1966: 531). While this notion mainly takes into consideration the behaviour of healthy people, Gochmans refers with his updated definition to a more holistic perspective on health behaviour as

'those personal attributes such as beliefs, expectations, motives, values, perceptions, and other cognitive elements; personality characteristics, including affective and emotional states and traits; and overt behaviour patterns, actions and habits that relate to health maintenance, to health restoration and to health improvement.'

(Gochman 1982: 169)

By this, he follows the health paradigm of salutogenesis in which health and disease are seen as two opposite extremes of a continuum and 'which sees each of us, at a given point in time, somewhere along a 'healthy/disease continuum' (Antonovsky 1996: 14).

Health promotion is ultimately linked to health behaviour as it describes among other aspects the daily routines and habits, preventive behaviours and how people seek and use health related information. While many theoretical models have been created to explain health behaviour (for an overview see e.g. Schwarzer 2011), Schwarzer's Health Action Process Approach (HAPA) (Fig. 1;

Schwarzer 1992; 2008) proved to be particularly feasible as a basis for developing a design model for health behaviour change. Among other reasons this is caused by its transdisciplinary setup and its focus on self-efficacy.

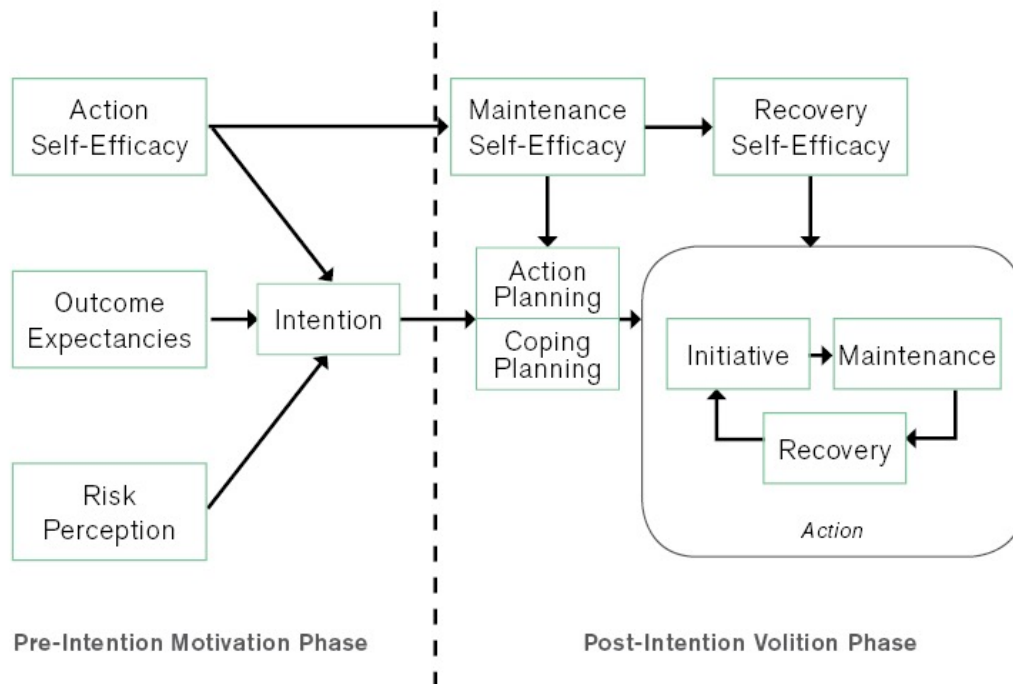


Figure 1: Health Action Design Approach (HAPA; Schwarzer 2004: 90)

The HAPA is divided into a pre-intentional motivation phase and a post-intentional volition phase. According to Schwarzer, during a process of health behaviour change three aspects are relevant for the development of intention in the motivation phase. (1.) Self-Efficacy describes one's 'conviction that one can successfully execute the behaviour required to produce the outcomes' (Bandura 1978: 141). (2.) Risk perception refers to the degree of one being aware of certain risks related to, for instance, the maintenance of a certain behaviour (such as smoking). (3.) Outcome expectancy describes one's assumption about which measures can be taken and which likelihood is related to these actions with regards to minimizing the before mentioned risks. If an obese patient is convinced that losing weight will reduce his or her risk of coronary heart disease he or she still must be convinced that a certain diet will lead to the weight lost (outcome expectancy) and that he or she is capable of complying with the dietary guidelines over a longer period of time (self-efficacy) in order to create intention.

Design model for health behaviour change (DMHBC)

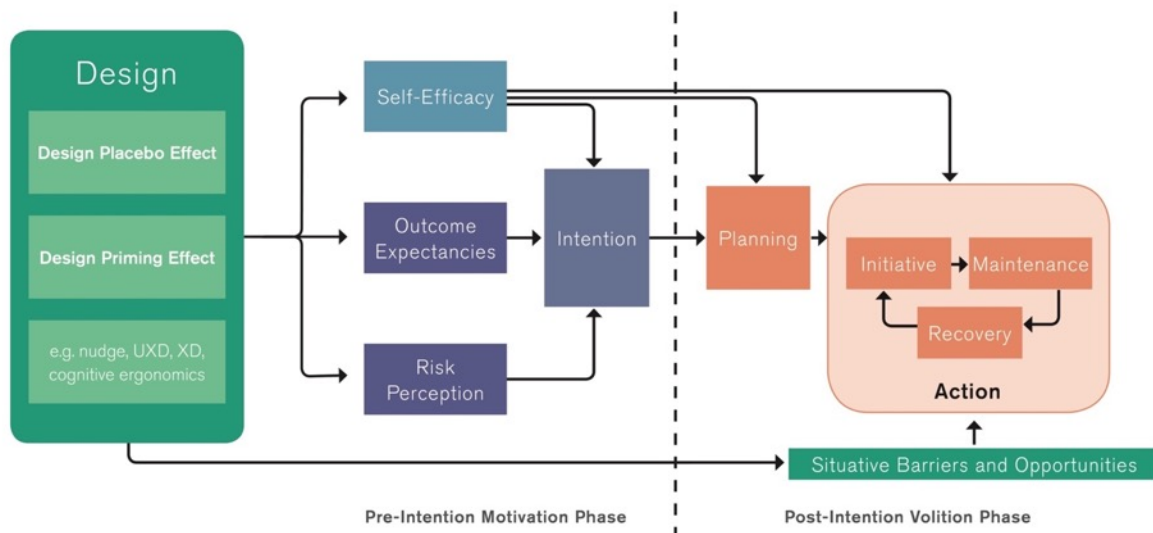


Figure 2: Design model for health behaviour change (DMHBC)

The herewith proposed design model focuses on design features that lead to or support health behaviour change or promote the maintenance of positive health behaviour. By doing this, the model follows a salutogenic (Dilani 2006) and psychosocially supportive (Ulrich 1997) design approach. This is rooted in an evidence-based (Stichler and Hamilton 2008; Malkin 2008) and research-driven understanding of design (Visocky O'Grady and Visocky O'Grady 2006).

While many design models refer to design elements that work in a direct visible way to support health behaviour (e.g. ergonomics to prevent harmful body movements) the DMHBC emphasizes subtle design cues that work rather indirectly based on principles from fields such as behavioural economics (Thaler and Sunstein, 2009), social psychology (e.g. Cialdini et al. 1990) and neuromarketing (e.g. Kay et al. 2004; Berger et al. 2008). While the HAPA can be described as a rather cognitivist model the DMHBC adds sub- and preconscious elements.

Following the HAPA four links have been identified in order to use design features as a efficient tool for health behaviour change. Three of these four aspects, namely (1.) self-efficacy (Bandura 1978), (2.) risk perception and (3.) outcome expectancy are located in the pre-intentional phase. It is assumed that design features might influence these three aspects already before conscious cognitive processing concerning these aspects has been taken place. The fourth link 'situative barriers and opportunities' is located in the post-intentional volition phase. Here both on a functional pragmatic as well as subtle cue-wise level design features act as environmental stimuli.

Design features as direct and subtle cues

Various design elements can affect the three pre-intentional aspects separately. Among others formal-aesthetic as well as conceptual features can act as a (a.) design placebo (Rehn and Schuster 2017) that create certain expectations that influence the perception of a given situation or (a.) prime (e.g. Kay et al. 2004; Berger et al. 2008) that activate certain mental representations.

With regards to (1.) self-efficacy, design features can for instance promote the impression of ease of use or the actual effectiveness of a certain behaviour. This creates an experience of mastery which in turn can support self-efficacy (see 'performance accomplishments', Bandura 1978: 143). In a more direct way, interactive systems that provide instant feedback of the effects a behaviour has can strengthen motivation and self-efficacy. Popular activity trackers can visualize for instance reached training goals and burned calories (see also Fogg 2003: 256).

In a similar way the design of an artefact or system can raise awareness for risks that are associated with certain behavioural patterns or emphasize the safety of an environment. Medical devices that are visually less complex, produce little noise and appear in a softer and more positive manner might reduce the subjectively (2.) perceived risk that a patient associates with the treatment. In a more playful way, concepts such as the 'HIV-Roulette' (Fogg 2003: 64-66) or 'Keymoment' (Laschke et al. 2014) try to point the users' attention to a particular aspect of health or risk behaviour.

In various ways design elements can influence the (3.) outcome expectancy. Virtual systems that simulate scenarios of different health behaviours can visualize the utility of a particular behaviour. Interactive visual systems, for instance, that simulate the use (or not use) of dental floss (c.f. Li et al. 2015) might change one's outcome expectancy by linking a certain behaviour to a particular result.

Situative barriers and opportunities

Both in a formal-aesthetical way as well as a pragmatic functional way design elements and features can act as situative barriers or opportunities. Situative barriers refer to objects or configurations that inhibit a certain health behaviour. An office canteen that only serves junk food displays situative barriers for healthy eating as it is not impossible but more complicated to eat healthy in such a setting. On the other hand, offering for instance free open access sporting devices in a public space (fig. 1) creates the situative opportunity and thus offers little threshold to become physically active.



Figure 3: Public open access sport devices as situative opportunities for physical activity in Singapore (Foto: Jonas Rehn, 2016)

Furthermore, these situative opportunities work on a mental level as well. With regards to spreading-activation theory (Collins and Loftus 1975) they can be seen as environmental cues (see e.g. Berger and Fitzsimons 2008) that activate a cognitive concept (see Bargh and Chartrand 2014: 317). By this, the concept of sport and physical activity has a higher accessibility (Higgins 1996) which might affect future planning and intention building.

Conclusion

Objects, systems and configurations affect health related thinking and behaviour in various ways. Thus, design decisions can directly and indirectly change a person's health behaviour. Focusing on aspects such as self-efficacy, risk perception and outcome expectancy during an early stage of the design process can be beneficial for health promotion. Understanding design elements and features as subtle cues that affect these three parameters as well as situative barriers or opportunities offers new potentials for designers of various specialties. With regards to a salutogenic (Dilani 2006) and psychosocially supportive design approach (Ulrich 1997) more research is needed to investigate practical applications of these effects for various settings.

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What are the effects of co-designing on participants' mental health and does uncertainty play a role in this change process?

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ABSTRACT *The purpose of this paper is to present the initial theoretical work undertaken in a PhD project which aims to understand co-design in the context of mental health, in particular the effects that designing has on participants with mental health problems, and the role that uncertainty may have on facilitating change in this context. The project was motivated by a series of co-design workshops that the author had facilitated in the past (2014-2017) with people with mental health problems who had reported some benefits. This experience suggested that by engaging with the inherently uncertain process of co-design in a calm and creative environment, new patterns of thinking, feeling and behaving may begin to emerge, often resulting in some progress in participants' recovery. In this paper, an interdisciplinary review of relevant literature is presented alongside a speculative discussion of how and why designing may have an impact on mental health, specifically looking at the potential role of uncertainty in this process. We propose that uncertainty could be a key concept both as a potential explanatory factor of why change may occur in participants, and as a generative tool when drafting design activities for this target group. This review and discussion will inform the design activities that will take place in the collaborating mental health organization following successful ethics approval. Following an abductive approach, analysis will be oriented towards explaining what is observed in the co-design workshops, to generate an initial theoretical understanding of the mechanisms at play. The outcomes of the research should shed some light on the effects that designing could have in facilitating psychological change, and our understanding of uncertainty both in relation to design and psychology.*

Keywords: co-design, mental health, mental illness, uncertainty, psychology, recovery, theory

Background

The purpose of this PhD project is to better understand the effects that the process of co-design may have on participants who have mental health problems and construct theory as to why this could be the case.

A few projects had been published recently that describe the use of co-design principles within mental health, often facilitated by guidelines such as the Experience-based Co-design, which encourages the use of design methods by other professionals, for instance: (Larkin, Boden, and Newton 2015; Cooper, Gillmore, and Hogg 2016). Among the projects led by designers specifically within the mental health context, focus relied on developing appropriate design methods or describing the design outcomes (Kettley, Sadkowska, and Lucas 2016; Glazzard et al. 2015; Nakarada-Kordic et al. 2017; Kaasgaard and Lauritsen 1997), leaving the effects of participation on mental health users -aside general feedback- yet to be explored. We can nevertheless find some examples that investigate the psychological effects of participation among members of the general public (Corcoran, Marshall, and Walsh 2017) or those with physical conditions such as diabetes, (Hendriks, Dreessen, and Schoffelen 2016) or spinal cord injury, (Macdonald 2013; Langley et al. 2013). Most often, these collaborative design projects answer to a relatively specific brief, perhaps responding to a particular need or problem: for instance co-creation of an online resource with young people experiencing psychosis (Nakarada-Kordic et al. 2017). In the projects I facilitated in the past (Figure 1), the project began with a process of problem identification, an exploration of 'matters of concern' fuelled by the experiences of participants themselves, similar to what Sanders and Stappers (2012) describe as societal-value co-creation, mostly occurring very early in the process. Designing in general, but even more so at these earlier stages, requires a very peculiar relationship with not knowing, which makes uncertainty a paramount concept to consider as a start. As Dorst and Cross (2001) described, problems and solutions co-evolve, and not only designers are often unaware of how to solve problems but these may also be unknown beforehand.

In relation to psychopathology, the implications of this concept seem all the more profound, as indeed much of uncertainty research has been undertaken in relation to mental health (Tracey and Hutchinson 2016), with research ranging from existential psychology to psychiatry following a wide variety of methodological and epistemological approaches.

Unfruitful efforts to situate observations on how people engage and experience open goal designing within existing narratives inspired me to consider the relevance of uncertainty and its associations to change in this context, especially considering that reflections from participants also seemed to portray periods of confusion preceding change. As May (1950) described, a shift in one's attitude toward uncertainty will indicate a break with past scripts and patterns of behaviour.

Acknowledging the intuitive nature of these initial ideas, a further analysis of these subjects led to some common themes across disciplines. Although someone could criticize the overly diffused complexion of this brief review, it is important to note that theoretical breadth is encouraged to

enrich the abductive possibilities of research (Henwood and Pidgeon 2003), and help inform alternative theorizations.



Figure 1: Co-design workshops at a previous project

Uncertainty and change:

Uncertainty has been studied in a variety of ways both within Psychology and Design. Taking an interdisciplinary approach, literature has been revisited through the lenses of whether it is concerned with uncertainty as an experience or as a tool. This strategy is oriented towards later stages of the project. Hence, when having to code and analyse participants' data alongside literature, it is unlikely that a disciplinary matrix will prove as advantageous as a phenomenological one. What is the existing knowledge about how uncertainty is experienced (uncertainty as experience) or how uncertainty is used (uncertainty as tool)?

If we were to discuss with someone their personal experiences of uncertainty, we would likely encounter value statements in their narratives, sometimes embedded in the language used– e.g. *dealing* with uncertainty. In fact, not only do different people experience uncertainty differently, but the same individual may relate to it in various ways depending on the context (Durrheim and Foster 1997). Bar-Anan et al. (2009) found that with increased uncertainty, subjects showed stronger affective reactions, both negative and positive, thus the more uncertain someone feels, the stronger their emotional response.

On the other hand, although context may play a role in how uncertainty is experienced, some individuals appear to struggle particularly in the face of the unknown, so much so that psychopathology is sometimes measured by reference to the nature of someone's relationship with uncertainty. For instance, pathology, according to Gordon (2003), arises from the avoidance of uncertainty, and trying to create certainty where there is none. From a completely different epistemological and methodological standpoint, Mcevoy and Erceg-Hurna (2016) have found the construct of 'intolerance to uncertainty' to be a characteristic across various diagnoses of mental illness, and White and Gumley (2010) associated higher uncertainty intolerance in individuals with psychosis with more negative perceptions about their experiences.

Nevertheless, not all experience of mental illness has been associated with intolerance of uncertainty. Often mental illness and creativity had been associated with a high tolerance for ambiguity (Abraham, 2014).

Gabora (2016) argues that arousal-provoking uncertainty can be experienced negatively as anxiety or positively as a wellspring for creativity (or both), and articulates how this phenomenon explains creativity. Indeed, Cash and Kreye (2018) have pointed out that designers respond to fluctuations in uncertainty perception by progressing within and across design actions. The study findings evidence uncertainty perception as a potential causal mechanism driving the progression of design activity and Tseng and Ball (2011) suggest this ability to use ambiguity as a generative element increases with practice. Interestingly, a changing relationship with uncertainty has been studied in relation to the development of designer identity in students (Tracey and Hutchinson 2016). Participants demonstrated increased positive orientation rates as the course went along, from (67% positive or mixed) to (79% positive or mixed), although the authors do warn that this could also be a result of unconscious bias, as students try to align themselves with perceived qualities of what makes a good designer. This research is poignant as it depicts how uncertainty as an experience is transformed into a tool by designers.

Many of the common design tools make use of uncertainty some way or other. For instance, Inoue et al. (2017) describe how the uncertainty of visual information presented externally can facilitate design reasoning, as designers are able to find semantic meanings and develop designs from meaningless geometric forms.

When engaging non-designers, they may or may not be able to experience uncertainty in such ways to spontaneously drive the design progression. In the context of co-design, the design process is facilitated via the use of tools and methods, which help participants orchestrate their skills in such way to perform in a designerly way. Along these principles, tools used in earlier projects in mental health had been revisited against the concept of uncertainty. For instance, *bodystorming* activities may generate a sensation of embedded uncertainty, but their playful nature reduces epistemological uncertainty (awareness of lack of knowledge on a subject). Hence, whilst designers may engage with uncertainty in ways that drive design activity spontaneously, participants could be encouraged to do so through design tools, and it is possible that this process enables some form of change on them as a result.

Usually, we tend to think of the designer as the subject rather than the object of change, hence Simon's famous definition: 'Everyone designs who devises courses of action aimed at changing existing situations into preferred ones.' (Simon 1969). Nevertheless, the transformative impact of immersion in the creative process can bring about sweeping changes to that second (psychological) level of complex, adaptive structure that alter one's self-concept and view of the world, extending far beyond the 'problem domain' (Gabora 2016). Whilst designers are used to engage in these processes and may not report changes in themselves, when non-designers are engaged in co-design via toolkits that enable non-verbal communication, the transformation that takes place is been described as remarkable, invariably positive and often therapeutic (Sanders 2000).

Although, as described by Higginson and Mansell (2008), why people change psychologically whether that is result of therapy, a result of psychotherapeutic intervention or during natural recovery, remains unknown, thematic analysis across diverse strategies helped draw some parallels with design and inform theoretical insights. Across the literature, perhaps the most salient theme figuring as important for psychological change is meaning-making. Meaning-making was identified key for psychological change in studies in art therapy (Forgeard et al. 2014) in posttraumatic growth and stress related growth (Linley and Joseph 2011; Helgeson et al 2006), participatory design (Hendriks et al. 2016), psychological change as a result of everyday life (Gianakis and Carey 2011; Higginson and Mansell 2008). Most interestingly, is that literature on psychological change (Linley & Joseph 2011) specifies that searching for meaning by itself is not associated with positive change, and the person must engage in more complex reflexive processing that will allow new meanings to emerge.

Here is the key element. As for emergence to happen (e.g. emerging new meanings) it follows that no full conscious control or awareness is assumed by the subject, or -in the case of a group- by any given subject alone. It is likely that those that engage in complex, reflective processing experience uncertainty when old patterns of thought, affect and behaviour are disrupted, and new ones emerge, when certain meanings are challenged and new ones emerge. It is also possible, that designing is a particularly effective way to navigate this process, due to the generative relationship with uncertainty and its fundamental purpose of generating change.

A tentative conceptualization

It is clear from the review that there is high variability on how uncertainty is experienced, which has been associated to context, affect, psychopathology and creativity in different ways, but how do these variables relate to one another? In which ways can uncertainty (its presence, its variability or its transformation) be used as a tool, and could this be reflected on peoples' experiences, perhaps even facilitating some form of change and recovery as a result?

People with mental health problems may show unhealthy patterns of thought, affect or behaviour which are often resistant to change via treatment and/or therapy. Rather than addressing these

problems directly, design may provide an opportunity that encourages participants to engage in new patterns of thinking, feeling and behaving that are driven by the design process, which makes generative use of uncertainty perception. Arousal-provoking uncertainty is no longer experienced as anxiety, but as a driver for design activity. Participants are now less resistant to complex reflective patterns which are associated with the emergence of new meanings. Change in participants is no longer the objective of engaging with design activity, but the side effect of their efforts to change something else – ‘existing situations into preferred ones’.

Next steps

Many more conceptualizations can be articulated to understand why participants with mental health problems may be affected as a result of engaging with design.

This review is meant to introduce one original theoretical framework based on a thematic literature review and inspired on personal experiences as workshop facilitator in mental health. The intention, nevertheless, is to continue this research process by gathering data which will include theories of participants themselves. By encouraging participants to reflect on their own experiences, they will likely articulate their own associations and reasons to explain any effects. As Tavory and Timmermans (2014) outline, the theoretical frameworks of the people under study can prove more illuminating and inspiring than academic theorizing.

In the following months, design workshops will be organized with clients of the collaborating charity. Via a variety of mixed methods such as standardized questionnaires, participant observation and interviews, data will be gathered about their experiences. This will be analysed to generate tentative explanations about the phenomenon, aiming at construction of theory. The results of this project may inform strategies to aid recovery, and may contribute to the wider area of co-design for health by providing some evidence of how engagement on design projects affects participants, and how facilitators can use tools to enhance their experiences.

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The Design of a Wearable Robotic Upper Limb Stroke Therapy Device that Addresses Acceptance and Initiation of Use.

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ABSTRACT *This study investigates patients' acceptance of a robotic device for stroke rehabilitation and how its design elicits initiation of use of the affected upper-limb. Stroke is one of the leading causes of long-term disability globally. Stroke affects the brain and motor function. Patients often don't receive the recommended amount of therapy, which robotics have the potential to deliver through real tasks and digital games. Patients and clinicians can have negative perceptions of these new technologies, which may be preventing initiation of use and acceptance of these new devices. This study addresses some of the barriers to the design of new medical technology devices for stroke therapy and the implications that may have on delivering healthcare.*

Clinicians and patients were interviewed through stroke clubs. Using an existing robotic acceptance framework, criteria were constructed to produce initial concepts through an iterative design process. Prototypes were assessed with clinicians and patients to then create a final design.

This paper presents the main findings from designing and testing the prototype with stroke patients; including ease of use, how acceptance and initiation of use were implemented. We discuss a framework for robotic acceptance to designing future wearable robotics for stroke rehabilitation.

Keywords: *design, stroke, Stroke therapy, Upper limb rehabilitation, acceptance, stigma, initial use, change.*

Introduction

Stroke is a leading cause of disability, and occurs predominantly in older adults (Feigin et al. 2014; National Heart Lung and Blood institute 2016).

Stroke leaves patients with long term impacts including reduced motor function. The majority will have impaired upper limb function (Weiss 2010). This impedes patients' ability to carry out daily tasks and requires therapy by clinicians, devices and aids for recovery (Stroke Foundation of New Zealand and New Zealand Guidelines Group 2010; Kwakkel, Kollen, and Wagenaar 1999).

Patients are not receiving the recommended amount of therapy for recovery. 23-32 repetitions of a singular exercise per day instead of 400-600 (Kimberley, Samargia, Moore, Shakya, & Lang, 2010) (Lang, MacDonald, and Gnip, 2007), and are receiving 2 hours 45 minutes less than recommended (Australian Stroke Foundation, 2017; Stroke Foundation of New Zealand, 2010).

Robots are increasingly being proposed to fill therapy gaps; they can measure, assess, support recovery, and maintain independence of older adults (Wu et al. 2014; Blackman 2013). Perceptions of robotics can be negative, affecting acceptance (Wu et al. 2014). In general, this is not addressed in current robotics, however, design in medical devices can improve comfort, aid therapy and increase acceptance and uptake by focusing on design (Vaes, 2014; Smarr et al. 2012; Wu et al. 2014). The design is important to the user perception, leading to higher acceptance of the devices (Wu et al. 2014), and increased uptake. The outcome being increased therapy received, leading to motor function recovery.

This study investigates the design of wearable stroke rehabilitation robotics to increase acceptance and initiation of use (Lemke, Rodríguez Ramírez, Robinson 2017) of a pre-existing system. The robotic system manipulates hand grip using electronics (Figure 1), to pull a system of artificial tendons (strings) (Rajendran, Hollitt, and Browne 2011). It can deliver passive motion, and assistive motion which finishes patient movement (Rajendran, Hollitt, and Browne 2011). The device (Figure 1) delivers repetitions for therapy and everyday activities, and data can be recorded. There has been some consideration to the cost, size and weight, but not into how the device is perceived by patients and clinicians.

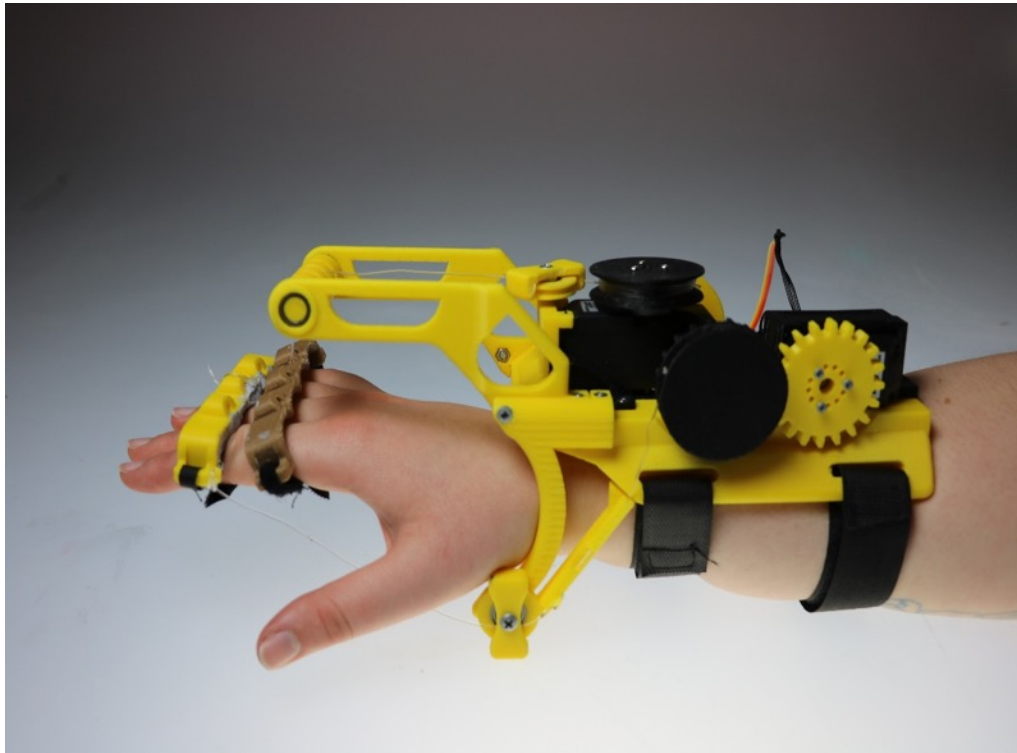


Figure 1: pre-existing robotic prototype to be redesigned in this project to increase acceptance in users. Upper strings (set 1) use a motor to pull up and open the hand. The lower arms pull the fingers forward and into a grip using string (set 2).

Methods

Research through design (Krogh, Markussen, and Bang 2015) was chosen for the overarching design process methods including iterative design (Rodríguez Ramírez 2017, 14).

Semi-structured interviews and Expert Reviews with Clinicians (Kuniavsky 2003, 447) were used to gather qualitative and quantitative data. To gain insight into therapy practices and how clinicians use robotic devices Thematic analysis was used to interoperate data (Alhojailan 2012, 40–45) and create design criteria.

A Robotic Acceptance survey as used as a framework then adapted into interviews (Wu et al. 2014, 804) to test our robotic device designs.

Results

Design process

Acceptance was explored through iterative design methods focusing on our constructed criteria. Features of everyday universal products to wear on their upper limb were analysed (Vaes 2014).

Our final prototype encompasses aspects of gloves (Figure 4), medical braces and sports protection (Figures 5-9). Other product features including jewellery were also considered.

The prototypes developing aesthetics and function were explored through drawings, and prototyping with 3d printing of components on and with fabrics. The focus was on designing for features that were important to the users' acceptance which included ease of use, promoting acceptance and initiation of use. Velcro was found to be the easiest technique to understand and use for both patients and clinicians in the don (putting on) and doff (taking off) process. This combined with a simple slide on under sleeve with attachment locations and straps that position and support the robotic components (Figure 5, 6 and 9). There was also consideration for comfort, cleanability, profile and weight.

The undersleeve is tailored for fit, padded and lightweight sections for comfort, and the positioning and support of the robotic components, and is removable for cleaning (Figure 5 and 9). The robotic components have been reduced in profile, re-designed to prevent strings blocking the grip (Figure 2a, 2b, 3 and 9), reducing the cumbersome arms (figure 1), and providing cohesive form, aesthetics and attachments.

The final device aesthetics, function and usability are designed for both use at hospital and at home for therapy and daily tasks (Figure 9).

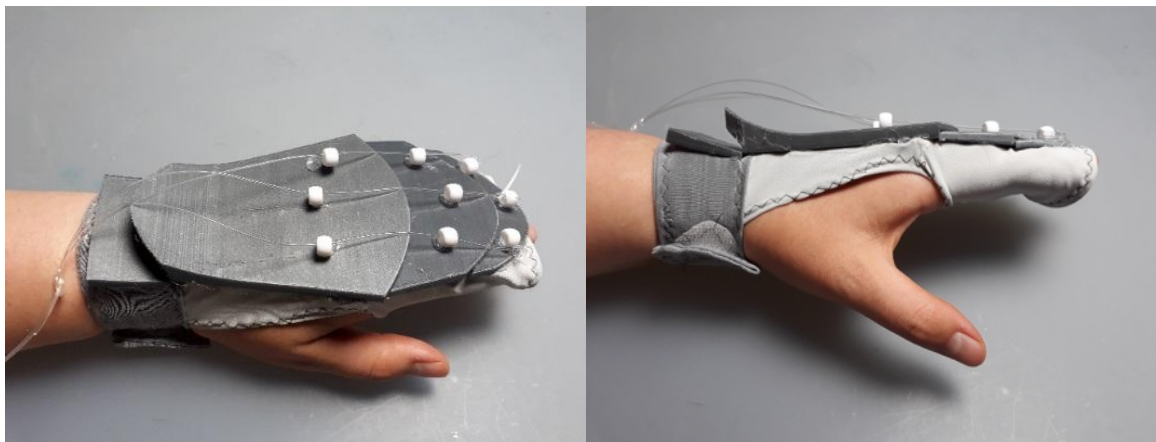


Figure 2a: armadillo plates prevent hyperflexion

Figure 2b: string pulls, the hand opens

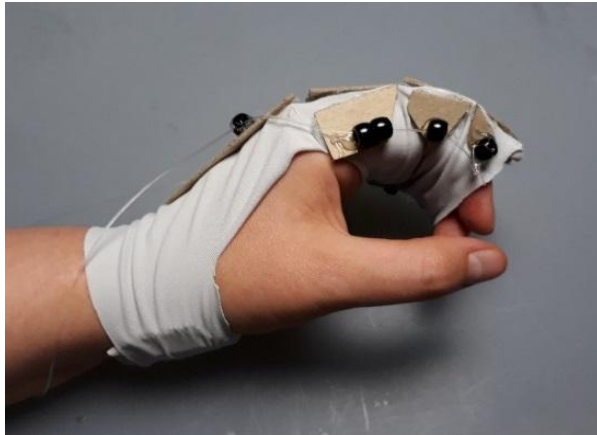


Figure 3: string set 2 helps close hand



Figure 4: glove with palm/fingertips free to grip



Figure 5: Tailored sleeve, removable components , stitched markings for reassembly and black padded attachment points .



Figure 6: pulling on the sleeve with components attached



Figure 7: 'wrap' Velcro don/doff reduces strap complexity

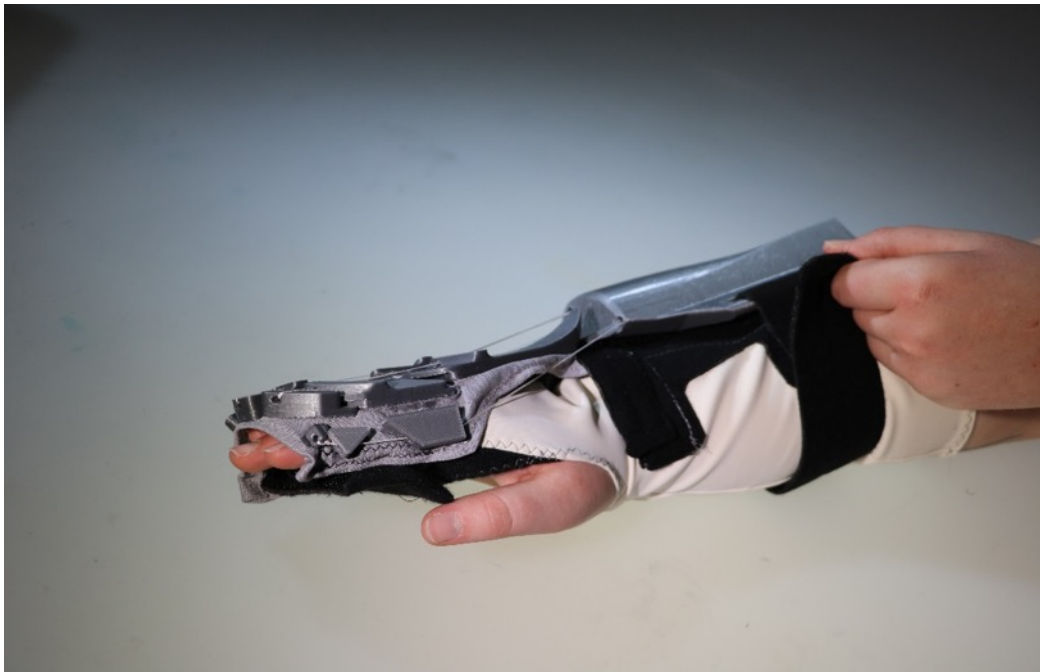


Figure 8: adjusting the robotic support strap



Figure 9: new design of device

Testing

Testing was carried out through a series of interviews and testing sessions, that were thematically analysed for design criteria. Participants were accessed through stroke clubs and conferences. Inclusion criteria for patients were mild weakness of the upper limb on one side of the body, one stroke event and high communication ability, and for clinicians, involvement in upper limb stroke therapy. Participants read information sheets and signed consent forms. Participants involved were three patients and three clinicians.

Interviews were carried out in patients' homes, clinicians' offices or digitally. Prototypes were introduced in order, and participants could choose to touch and try on prototypes. Interviews were recorded with audio, photo and or video recording.

The key factor from the framework is that perception of robotics is an indicator of robotic acceptance (Wu et al. 2014). Patients were positive about robotics in general prior to being introduced to prototypes, and had neutral or positive feedback on the designs. Other factors include use of aesthetics of items generally worn on the hands, drawing from universal design (Vaes 2014).

This study found design criteria for acceptance are: ease of use, comfort, lightweight/portable, independent use, unit profile, cost (see pre-existing), cleanable. These criteria were implemented back into the design process (see design process).

Other found factors included: aesthetics unimportant and that the device delivers the promised function, and recording measurements.

Discussion

The design of robotics needs to consider the impacts on subjective and social factors as well as delivering the task (Kiesler and Hinds 2004, 4–5). Although The aesthetic features that seemed important in the literature (Vaes 2014); they were not as important to the interviewed individual's acceptance and initiation of use of the prototypes as indicated by the literature. How the device is applied was the factor important to all participants, among other found criteria. There were also different considerations needed for clinicians including the addition of measurement for patient outcomes.

The limitations of this study are: the focus on the structure holding the robotics and attachment rather than programming the robotic components itself. Prototypes tested with patients were about the initial reaction and don and doff, not testing the functioning of the robotics. Patient participants were all male, and accessed through stroke clubs when an outpatient. All participants chose to be involved in a robotic study which may indicate a possible elevated robotic acceptance rate, and potential reduced importance on the aesthetics.

Future studies should explore a larger patient population and test individuals with both low and high perception of robotics.

Conclusion

Stroke is a major cause of motor impairment, and acceptance and initiation of use are significant in the uptake therapy devices. The study found that users valued ease of use, comfort, lightweight, low cost and the ability to wash the product. The product aesthetics were not highly valued but were improved as an outcome of design process. The device exterior was developed into a final model that was reduced in profile and the attaching strings streamlined and attached to familiar sleeve base to provide a more functional and easy to use device for the patients, and incorporation of measurement data providing potential improved clinician acceptance, increasing device use in practice. Product design could address barriers and enable increased therapy delivery, accessibility and use of devices.

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Between Care and Control: The consequences of digitalization for person-centred care

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ABSTRACT ONLY Drawing on our experience and critical analysis of designing a digital person-centred self-management support intervention, this paper deals with consequences of implementing technologies with a potential for increased control into healthcare. Re-working and equalizing the power relation between healthcare workers and patients through person-centred care and other similar care models are on the increase. These models often draw on holistic approaches that reaches beyond the biomedical understanding of the body. They also often account for subjective matters, personal aims, abilities and this movement can be seen as going beyond the biomedical paradigm where subjective matters often are neglected in favour of objective measurements (Ashcroft och Van Katwyk 2016).

Alongside this development there is also an increased interest for digital health technology. Digital health today includes a large variety of technologies, many with the potential to change the very foundations of healthcare. Devices and systems for self-monitoring, data collection and analysis through AI and big data are among the technologies that are trending. However, what the emerging technology in the context offers is often more associated to measuring and monitoring the body, less on the person (Rapp och Tirassa 2017). We argue that this reflects a transition and change of focus towards control rather than care, and thereby challenge person- and patient centred care models. Based on our findings, we theoretically discuss possible trajectories of implementing such technology and its consequences for person-centred care and other similar care models.

Keywords: Co-creation; design research; ethical frameworks

Clinicians' Perspectives on What Influences Uptake of New Technologies into Rehabilitation Practice

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ABSTRACT *From apps to gamification to robotic exoskeletons, rehabilitation technologies are being rapidly developed, yet many never find their way into routine clinical practice. While patients may be the primary end users, clinicians play a key role in introducing and supporting rehabilitation technologies. Conceptualizing clinicians as a key user group in the design process may be critical to future uptake. As such, we aimed to explore the experiences and perspectives of clinicians regarding the implementation and use of rehabilitation technologies.*

We undertook a qualitative descriptive study using semi-structured focus groups and interviews with 27 rehabilitation practitioners. Data were analysed using conventional content analysis.

In this paper we will discuss our findings and their implications for the design and development of rehabilitation technologies.

Considering implementation at the outset and drawing on an in-depth understanding of all end user perspectives will likely lead to the development of rehabilitation technologies which are more tailored and responsive to the context of use.

Keywords: rehabilitation, technology, implementation

Introduction

A growing body of evidence showcases the value of new technologies in a rehabilitation context (Wolff et al. 2014). Potential benefits include minimizing access barriers, measuring improvements, reducing the burden on health care professionals, increasing patients' motivation, and increasing the opportunities for rehabilitation (Wolff et al. 2014; Ogourtsova, Archambault, and Lamontagne 2017). As a result, there is significant interest in the development of new devices for rehabilitation.

Despite this, many new technologies do not make their way into clinical practice, or if they do they are often not routinely used (Liu et al. 2015; Ogourtsova, Archambault, and Lamontagne 2017; Langan et al. 2017). Exploring why this happens is a growing area in the literature. A range of approaches have been used seeking to better understand the transition of a device into clinical practice including drawing on relevant theoretical frameworks (such as theories of normalization and integration) (May and Finch 2009) and exploring stakeholder perspectives.

Involving users throughout the design process can help make new technologies responsive to end user's needs (Hill et al. 2017). These participatory practices are hypothesized to overcome the issues around use and implementation (Wolff et al. 2014). However, typically the patient is seen as the primary end-user with little consideration of the clinician as end user (Liu et al. 2015; Hill et al. 2017; Langan et al. 2017). Often it is the clinician who evaluates, introduces and supports patients to use new technologies. As such, the clinician may play a critical role in successful uptake of rehabilitation technologies and their perspectives should be given explicit consideration in design and development.

The success of rehabilitation technologies may be enhanced through a better understanding of clinicians' perspectives and recognising them as another important user group. The intent and purpose of this research was to explore in-depth the perspectives of clinicians regarding their perceived constraints and opportunities for integrating new technologies into rehabilitation practice.

Methods

Design

This study used Qualitative Descriptive methodology which draws on the general tenets of naturalistic inquiry. It is argued to be a useful approach for exploring the perspectives and experiences of a phenomenon (Sandelowski 2000). The aim is to produce a rich description of events and the meanings people ascribe to those events which is argued to have pragmatic utility when wishing to produce research findings which can be formative to future practice (Sullivan-Bolyai, Bova, and Harper 2005). This was consistent with the ultimate goal of this research which was to inform the practices inherent in the design, development and implementation of new

rehabilitation technologies. This research was conducted in several locations across Aotearoa New Zealand. Ethical approval was received from Auckland University of Technology's ethics committee (16/3480).

Sampling and recruitment

People were eligible to take part if they were currently working in the rehabilitation context, clinically or in a management role. Purposive sampling (Patton 2002) aimed to capture a breadth of experiences across a range of key characteristics including years of experience, profession, clinical setting, source of healthcare funding, geographic location, varied experiences of integrating new technologies and cultural perspectives. An invitation to take part was circulated to potential participants via professional networks. Those interested were encouraged to contact the research team, after which they were sent a participant information sheet and given the opportunity to ask further questions.

Data collection

Data were collected using semi-structured individual and focus group interviews. These interviews aimed to explore perspectives regarding what helps or hinders uptake of new technologies into rehabilitation practice and were conducted by two members of the study team (KS and NK). An interview guide supported the conversation, however the interviewer was responsive to the participant narratives exploring topics raised by participants. Examples of questions included 'how would you describe your experiences of trying to integrate new technology into rehabilitation practice?' and 'in your opinion, what are the key things that facilitate uptake of new technologies into practice? What gets in the way?' The interview guide was refined iteratively through the data collection process in response to earlier data. Interviews were audio recorded, then transcribed verbatim.

Data Analysis

Data was analysed using conventional content analysis (Hsieh and Shannon 2005). All authors engaged in data familiarisation by listening to a subset of audio recordings, and noting down key ideas and concepts present in the data. Following that, a meeting was held to discuss the range of key concepts identified to inform the development of a coding framework. All transcripts were coded by the first author using the coding framework, generating new codes when an existing code did not fit the data. Finally, a series of meetings were held to discuss codes and group them into meaningful clusters, each time checking against the raw data to ensure robust interpretation.

Findings

Twenty-seven people agreed to take part in the research. A summary of participant characteristics are included in Table 1. Of these, 19 took part in four focus groups and the remainder took part in an individual interview. Participant age ranged from 24 to 69 years (mean: 41 years) and years working in current role ranged from 3 months to 45 years (mean: 7 years). The majority of participants worked primarily with people with neurological injury or illness (n=20), including traumatic brain injury, spinal cord injury, stroke and concussion. A number of participants worked across a range of populations including neurological, musculoskeletal and cardiorespiratory conditions (n=6). One participant worked with people with visual impairment. Participants work spanned paediatrics to older persons' healthcare. Four participants were in managerial positions.

Table 1. Participant Characteristics

Characteristic		n
Ethnicity	NZ European	23
	Māori	2
	Other	7
Profession	Physiotherapist	13
	Occupational therapist	7
	Speech and language therapist	2
	Psychology student	2
	Clinical psychologist	1
	Rehabilitation assistant	1
	Nurse	1
Clinical Setting	Acute hospital	2
	Inpatient rehabilitation	4
	Outpatient rehabilitation	2
	Community rehabilitation	18
	Mixed	1
Receptive to technology	Strongly agree	17
	Agree	10
	Neutral	0
	Disagree	0
	Strongly disagree	0

(Note: people could self-identify with more than one ethnicity).

Cost, Evidence and Practicalities

Discussion centred around three key areas which at face value drove clinicians' decision to implement new rehabilitation technology into their clinical practice including; affordability, having evidence that a given technology is better than existing methods, and that it is practical and easy to use.

Cost was frequently mentioned as a barrier to implementing new technology and was referenced at a patient, service and funder level. People also commented on funding priorities in a resource-constrained healthcare environment.

'We [the service] just won't be able to afford really expensive technology, so it has to be affordable.' – Heather, managerial position, community.

Some clinicians reflected on how different healthcare funding structures impacted their ability to implement different technologies for different patients.

'I guess [accident compensation scheme] will get the best chair that meets the need of that person, and covers as many domains of their life as possible. Whereas somebody who is a [public healthcare] client, they will get the chair that is the right size and the chair that is, you know, going to get them where they need to go. They will get that instead of a brand new custom chair.' – Wendy, physiotherapist, inpatient rehabilitation

Clinicians described being 'hamstrung by evidence-base' (Simon, occupational therapist, community) before they were able to utilize new technological innovations. Others expressed a desire to wait for unbiased evidence of efficacy:

'[Evidence for a gamified upper limb rehabilitation device] came from research fed into by the creators and so there's the financial involvement in those studies to some extent. Which raises the eyebrows a little bit. So I think you are kind of waiting for it to either grow, and perhaps external researchers provide evidence of its success, and sometimes it seems to just fizzle away. So almost there's a bit of a waiting... to see actually, has it been tested independently by researchers?' – Mary, physiotherapist, outpatient

In some instances, a new piece of technology was perceived as too complicated to implement into practice, or more high-tech than was necessary. It was argued that if it was assessed as being too hard to work with, there was a tendency to revert to 'old school' (Julie, occupational therapist, community) methods to achieve the same thing. One therapist illustrated this reflecting on their experience of having a dynamic orthotic device for the wrist and hand given to the clinic which wasn't used:

'To be fair, we hadn't done the training for [the device], but I could understand the principles in terms of using it. But I thought it was a complicated way to achieve something that might be able to be achieved in simpler ways.' – Samantha, managerial position, community

As this participant summarized her experience of the device and watching other clinicians 'not really try to engage' with it, she encapsulated a number of the concepts contained in this theme:

'Most people work in a [health board] and can you afford to pay \$4000 for a piece of equipment that might be used by 10% of your patient population and be more complicated to put on and use? [...] If things are too difficult, too complex, too expensive for the amount of use, those are almost insurmountable barriers for integration of the technology.' – Samantha, managerial position, community

Interrogating Perceived Value

While at face value these findings provide guidance for developing new technologies for rehabilitation, they do not capture the complexity of the decisions clinicians were making. This theme was constructed to illustrate that a clinician's wider context significantly affected their perceived value of technology in rehabilitation. There were a number of beliefs and underlying assumptions clinicians appeared to hold which contributed to this perception, and thus, the likelihood they would attempt to integrate it into routine clinical practice. This includes beliefs regarding what constitutes rehabilitation, their perceived role in that, and who and what is given priority in the decision.

Some clinicians saw their professional identity as one of expert, where they hold specialist knowledge. In this context technology supporting their perceived role as an expert was prioritized. Unfamiliar or complex technology was disregarded if it made clinicians 'feel like a substandard therapist' (Melissa, physiotherapist, inpatient rehabilitation). Similarly, there was tension between the clinical role of supporting autonomy, but wanting to maintain control of a clinical interaction or process:

'We have this sort of dichotomy where we want the patient to be independent, to be able to put the equipment on themselves, and operate it themselves, but for us to be able to lock it, set it, and control it. As a therapist if it's therapy equipment then you have to be able to adjust it so that it's personalized, so that you know you're still doing therapy for the person ... I think often as therapists we do like to control.' – Natalie, physiotherapist, inpatient rehabilitation

Some recognized this dichotomy and explicitly withheld their opinions about the value of a rehabilitation technology if it was something the client valued. 'I wasn't going to say anything critical, [about an app where evidence was perceived as refuting benefits] because if she is feeling that is helpful, great!' (Kimberly, occupational therapist, community). While in some cases,

observing clients engage with technology helped to challenge the clinician's assumptions about the outcomes one might privilege in determining the value of technology.

'When I was looking at the [robotic exoskeleton], I was like "are you kidding? It takes 5 minutes to stand up and walk 10 metres! Why would you do that?" and the guy in the wheelchair looked at me and said "because you can" and I was like, "there you go - I will shut my mouth now", and I have to do that... because, like I said, I am quite critical with it all.' – Melissa, physiotherapist, inpatient rehabilitation

These perspectives provide insight into how different clinicians viewed legitimate rehabilitation in relation to new technology devices, including their roles and what outcomes are given precedence.

Discussion

This study provides an examination of clinicians' perspectives regarding what helps and hinders the uptake of rehabilitation technologies in clinical practice. These findings go beyond identifying barriers to implementation and interrogate what value clinicians place on technology in rehabilitation and how that is constructed. How they determine value appears formative to their decision to implement new technologies into practice.

Clinicians in this study articulated the need for new technologies to be affordable, have robust evidence supporting their use, and be easy to use in the clinical context. This is consistent with other literature in this area (Liu et al. 2015; Ogourtsova, Archambault, and Lamontagne 2017; Langan et al. 2017; Chen and Bode 2011).

However, the second theme augments this existing knowledge, offering insight into the broader context within which clinicians make the decision to implement new technologies into practice. It is clear from these findings there are a number of complex, often implicit, value-based decisions being made by clinicians when considering uptake of new technology. New technologies had the potential to lack fit with a clinician's perception of rehabilitation or their clinical role, or force them to confront their differing priorities from their patients. Hill (2017) argues the meanings which patients attach to technologies can make or break their integration into everyday life. Our research shows clinicians also attach meanings to technologies, and more broadly rehabilitation, which play a decisive role in integration of technology into clinical practice.

Previous studies suggest the same technology features might appeal to both designers and clinicians (Wolff et al. 2014). While participatory design methods involving clinicians may capture these, if involvement is limited to discussing features and practicalities of use, they can fail to acknowledge the often critical role clinicians play in implementation. We argue that consideration of these complexities could influence design and development decisions to address issues relevant to implementation from the outset.

The strength of this study is in its in-depth exploration into the experiences and perspectives of clinicians. We aimed for diversity on a range of key sampling characteristics. While we achieved this on most criteria, we were not able to achieve the level of diversity we were hoping for in terms of cultural perspectives. In particular, we were seeking to involve more New Zealand Māori, the indigenous population, given they may have some unique and specific perspectives regarding the use of technology. Further, our participants had a range of perspectives regarding what constitutes rehabilitation technology which may have contributed to the reflections they shared. A high proportion of our participants worked with neurological populations which may limit the transferability of findings to other settings. As this research was conducted in Aotearoa New Zealand, the findings will be specific to that healthcare system and structure.

Conclusion

Despite evidence suggesting technology has the potential to improve outcomes and experiences of rehabilitation, many still do not find their way into routine clinical practice. This paper has presented two themes from a study exploring clinician's perspectives of integrating new technology into rehabilitation practice. While clinician's perceive affordability, robust evidence, and practicality as necessities in rehabilitation technology, this research shows that clinical decision making is much more nuanced. We conclude that technologies must also be designed to take into account the context, process, and values of clinicians in order to maximize the likelihood of becoming a part of routine clinical practice.

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A co-design investigation into Emergency Department Waiting Rooms

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ABSTRACT ONLY Ageing, social inclusion and wellbeing are timely themes creating new challenges for designers of the built environment. In addition, the advancement of digital technologies coupled with new care models (such as intergenerational living) have resulted in an ever-evolving awareness of the importance of designing buildings for a dynamic population. However, within the profession of design/architecture, there is a recognised lack of design insight based on the sharing of real-life experiences of buildings (in general) and care homes (specifically). Despite legislative statutes and design guidance, little is known from user evidence about how this can be achieved. Uncovering design challenges and successes is fundamental in improving quality of life and wellbeing for older people. Moreover, this evidence has the potential to ensure longevity of future buildings.

Focusing on themes of ageing, care homes, intergenerational living and digital technologies, this paper reports on methods adopted and findings elicited from an ethnographic study undertaken at a care home in Deventer, the Netherlands. The researcher spent a week living in this intergenerational, technology rich care home. Utilizing methods of observation, semi-structured interviews and visual tasks, data towards understanding the living experiences of older people in the care home was uncovered. The findings highlighted how cohesion between generations, enhanced social connections and the design of the care home, led to the reduction in loneliness, isolation and improved wellbeing and quality of life for residents. Integrating advanced technologies within accessible locations increased older residents' independence, sense of control and social connectivity.

This paper seeks to interest key stakeholders (such as policymakers, architects and developers), to encourage vital yet realistic change to benefit an ageing population's quality of life.

Keywords: ageing; social inclusion; wellbeing; digital technologies; intergenerational living; built environment

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Addressing Stigma and Marginalisation in the Design of a Toolkit for Opiate Overdose First Aid

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ABSTRACT ONLY *Opioid overdose is an international public health crisis that is impacting communities around the world. Access to supports such as harm reduction services, including first aid supplies and the opiate antagonist naloxone, can contribute to a coordinated response [1]. We aimed to design an open-access toolkit for use in point-of-care settings [2] consisting of first aid training for opiate overdose together with nasal naloxone. We collaborated with a range of stakeholders to understand the context in which opioid overdose occurs, the people and communities affected, and to identify opportunities to reimagine opiate overdose first aid training and naloxone access. We worked with community representatives and people with lived experience of opioid overdose, as well as stakeholders in family practice, emergency medicine, addictions medicine, and public health, synthesizing insights across stakeholder perspectives through the design process. The final prototype offers an integrated solution combining design outputs across digital and physical media for use in family practice, emergency departments, addictions clinics and community settings. The design process addressed issues of stigma and marginalization [3] challenging existing techniques. Addressing stigma and marginalization necessitated community engagement and relationship building with those with lived experience so that verbal and visual language could be addressed and contextual factors impacting design could be identified. This engagement took the form of both participatory design methods [4,5] as well as more discrete co-design techniques [6,7]. The need to integrate evidenced based protocols and insights from lived experience of opiate overdose (from both existing literature and through participatory and co-design techniques), with contextual insights from design research on point-of-care experiences, required a multiplicity of stakeholder engagement techniques and a positioning of the designer/design process as integrator. This paper will share some of the specific techniques and reflect on the designer/design process in creating a contextually appropriate solution one aspect of the opiate crisis.*

Keywords: overdose, stigma, co-design

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Diabetes is like one of our family members': Exploring metaphors in user narratives to inspire design

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ABSTRACT This paper aims to reveal the value of metaphorical content obtained from users as an inspiration source for designers. Within the framework of this study, metaphor is considered as the constitutive of our language, moreover, constitutive of our conceptual system on the basis of Lakoff and Johnson's (1980) approach. Studies related to metaphors within design research predominantly focus on how designers generate and utilize metaphors in their design processes (e.g. Casakin and Goldschmidt 1999; Cila 2013), and it appears that users' side has not been explored yet. Our research started by relying on the relevant findings of another domain, health sciences, where studies revealed the value of metaphor in easing communication, enhancing understanding of patients and creating therapeutic effects (Southall 2012). By transferring this knowledge to design domain, it is assumed that the metaphorical content provided from users can improve communication between users and designers, and inspire designers during the ideation process. This hypothesis is examined in a two staged study including diabetes patients and designers: an online survey about living with diabetes is conducted within an online diabetics' community, and then individual designers are asked to interpret the outcomes of the survey to develop ideas that can improve the lives of diabetics. Through an ethnographic content analysis (Altheide 1987) it is found that participant designers prefer to focus on user expressions with rich metaphorical contents and utilize these metaphorical contents to generate initial design concepts by providing deeper insights into users' understanding.

Keywords: user-centred design, diabetes patients, metaphor, idea generation

Introduction

In 'Metaphors we live by', Lakoff and Johnson (1980) argue that, metaphor is not only 'a matter of words', it is the constitutive of our language structuring our thoughts, understanding and everyday actions. In the context of user-centred design, this paper aims to explore metaphors in user narratives, and it attempts to reveal the value of metaphoric content obtained from users as an inspiration source for designers.

During a conversation with a diabetes patient and his wife, the wife said; 'Diabetes is like one of our family members'. The 'family member' metaphor of diabetes is considered very powerful in terms of conveying patients' perception of living with diabetes. Thus inspired us to investigate the potential of metaphorical content in the area of user-centred design research.

In this paper we begin by defining our conception of metaphor within the framework of this research and the theoretical position with regard to how metaphor functions. Then, we briefly mention studies related to metaphors within design research and introduce an overview on the related research regarding metaphors in another domain, health sciences, where studies revealed the value of metaphor in easing communication, enhancing understanding of patients and creating therapeutic effects (Southall 2012). After providing the theoretical background we explain our empirical study aiming at exploring the usefulness of metaphorical content in user narratives to inspire idea generation in design. In the final part, we discuss the outcomes of the empirical study by utilizing ethnographic content analysis, and then conclude with further research and possible implications.

Metaphors Users Live By

Our conception of metaphor is grounded in Lakoff and Johnson's approach: by building their theory on linguistic evidence, Lakoff and Johnson (1980) suggest that our conceptual system is 'fundamentally metaphorical in nature' (p.3), and metaphorical concepts structure our thoughts, our understanding and our everyday actions. Therefore understanding metaphors 'users live by' is considered highly significant, due to metaphors' constitutive function in our conceptual system, by extension, its potential to gain deeper insight on users' lives.

Studies related to metaphors within design research have been predominantly focused on designers, in particular on how metaphors are generated in design process (e.g. Casakin and Goldschmidt 1999; Cila 2013) and it appears that users' side has not been explored yet.

In order to investigate how users generate metaphors in their narratives and how these metaphors can be utilized in design research, we chose an online community of diabetes patients as our potential user group. Thus our research has started by relying on the relevant findings in the field of health sciences, where a considerable number of research studies focusing on the patient's use

of metaphor laid the groundwork on the significance of metaphorical contents in enhancing communication between patient and professional, supporting self-understanding of patient, easing articulation of sensitive subjects, and creating therapeutic effects (Southall 2012). The patients' use of metaphor is particularly investigated in palliative care research, covering subjects such as, life-limited patients' metaphorical utterances, the modes of communication patients use, the role of metaphors within a palliative care setting, and 'metaphor's therapeutic usefulness' (Southall, 2012).

Exploring Metaphors in User Narratives to Inspire Design

By transferring this knowledge from health sciences to design domain, it is assumed that metaphorical content provided from users can improve communication between user and designer, and provide the designers with a source of inspiration in the ideation process of design. In the study, we addressed two questions:

1. Do designers' approach differ when dealing with metaphorical expressions and direct expressions in user narratives?
2. Do metaphorical expressions of users' contribute to idea generation process in design?

These questions are examined in a two staged study including diabetes patients and designers: a survey about living with diabetes is conducted within an online diabetics' community, and then individual designers are asked to interpret the outcomes of the survey to develop ideas that can improve the lives of diabetics.

Obtaining Patient Narratives of Diabetes through Online Survey

For the survey with diabetes patients, questions were formulated to obtain information about the manifestation of diabetes; life style changes patients had to make and their feelings about these changes; their routines; their concerns and frustrations; difficulties and emergency situations they face; their wants and needs; and their perception of the disease. The survey consists of 17 questions and most of them were open-ended. 103 diabetics participated in this study.

Communicating Patient Narratives of Diabetes to Designers

In the second stage, answers provided from the online survey were communicated to 10 participant designers who are academics and practitioners in the field of Industrial Design. A brief text including introductory information about diabetes and the instructions related to the task was provided to participant designers. For the task, individual designers are invited to consider the answers of diabetics as a stimulus for design ideas that might improve the lives of people living with diabetes and then, they are asked to underline parts that they find interesting, surprising and/or inspirational; highlight parts that give them an idea for a design; and reflect their ideas, by taking notes and drawing simple sketches while going through the transcript. After completing

the task, follow-up interviews were realized to discuss whether and how these responses and narratives of diabetes patients inspired designers to think of new ideas.

Analysis and Interpretation of the Outcomes

The outcomes of the empirical study were analysed by applying ethnographic content analysis (Altheide 1987). Through the analysis and the interpretation of the outcomes, we found that:

1. Participant designers preferred to focus on user expressions with rich metaphorical contents more than they focus on direct expressions.
2. Metaphorical expressions of diabetes patients enabled designers to empathize with patients strongly.
3. Compared to direct contents, metaphorical contents' contribution to idea generation process was far more dominant.

Defining the Categories of Diabetics' Answers

Within the framework of this study, we categorized answers of diabetics into two: utterances containing direct expressions and utterances containing metaphorical expressions. The identification of metaphor has been broadly associated with detection of indirect meaning (Lakoff 1986, 1993; Gibbs 1993). Therefore, we accepted an utterance as metaphorical if one kind of thing is expressed in terms of another (Lakoff and Johnson 1980, p.5), if a lexical unit is 'used indirectly to convey a meaning that differs from its basic, direct application' (Steen, 2007).

Table 1. Answer categories and sample quotations

Answer Categories	Sample Quotations
Utterances containing metaphorical expressions	<p>'First, you need to learn how to become your own pancreas'</p> <p>'(Diabetes is) a friend you need to get along with'</p> <p>'(Living with diabetes is) like doing acrobatics'</p>
Utterances containing direct expressions	<p>'Don't panic and don't pity yourself'</p> <p>'Diabetes is about diet'</p> <p>'It is horrible to live with diabetes but I got used to it'</p>

Defining the Categories of Designer Notes

In order to analyse outcomes provided from the study with designers, two main categories of designer notes were defined: annotations and idea notes. Notes not relating to any design idea were regarded as annotations, which include summaries of some selected answers, notes about identified patterns, questions regarding diabetics' narratives, and articulation of emotions. Notes related to design ideas were regarded as idea notes and four subcategories of idea notes were identified.

Table 2. Idea note categories and sample idea notes. Categories were adopted from Celikoglu's (2015) dissertation by adding one new category -identifying opportunities.

Idea Note Category	Sample Idea Notes
Identifying Opportunities	[seesaw] 'would be my starting point if I'd design myth related' [life style] - 'this definition can be utilized'
Setting Design Criteria	'portability, easy access' 'can be regarded as an input for design language- psychologically safe'
Improving Existing Products	'an understandable feedback can be provided to prevent misuses' 'warning system'
Developing New Ideas/ Concepts	'measurement results can be monitored through an app by healthcare personnel

Designers' Focus of Attention in User Narratives

Survey answers consist of 1052 utterances of different participants: 952 of them were categorized as answers containing literal expressions and 110 were categorized as answers containing metaphorical expressions.

When looked at the frequency of marking (underlined and/ or highlighted), we found that, designers marked 24,72% of answers containing metaphorical content, and yet only 8,64% of answers containing literal content.

Table 2. Frequencies of marked contents in user answers

	Metaphorical Contents	Literal Contents
Total number of diabetes patient utterances	1100	9420
Marked utterances by designers	272 (of 1100)	814 (of 9420)

In the survey, there was a specific question directed to obtain metaphorical expressions related to living with diabetes: 'If we ask you to describe diabetes or living with diabetes in one or two words, what would you associate diabetes with?' which provided access to understanding how participants made sense of diabetes and how they feel about living with diabetes. This question was one of the most frequently marked questions.

Designers' Approach towards Metaphorical User Expressions

Through examining how designers tackled with metaphorical content, we will expand on the second and third findings and try to explain why metaphorical expressions of diabetes patients are considered useful in terms of enhancing designers' understanding of patients' experience (2), and how metaphorical expressions contributed to the ideation process (3).

First-person narratives of living with diabetes conveying metaphorical expressions allowed for an in-depth understanding, mainly because of the 'context-dependence of metaphorical interpretation' (Stern 2000). While designers were interpreting diabetics' metaphorical expressions, they had to delve into the narrative to make sense of the metaphor within its context. For instance, one participant designer highlighted the utterance, 'I would say, "Welcome to your new world" to people who has newly become diabetic', explained how she interpreted the utterance as follows:

'They see it [diabetes] as a whole new world [...] they also complain about people who does not have diabetes because of their lack of understanding. I thought maybe this is the reason why they see diabetes as a new world. Like a parallel universe, they think of a diabetes universe... I highlighted that, because strengthening relations between these universes is important for design.'

As can be seen in the exemplified case, while approaching to a metaphorical expression, designers first analysed and interpreted the metaphor within its context and then tried to translate their understanding in a way that can be incorporated in further design ideas.

While designers were dealing with the answers of the question, 'what would you associate diabetes with', they have gained important insights regarding living with diabetes that enriched their idea generation process. Many insightful answers were acquired from this question, such as 'healthy living', 'mindfulness', 'sweet curse', 'military discipline', 'responsibility', 'open prison', 'octopus', 'sword above the head', 'a mountain hard to climb', 'unavoidable friend', 'balance', 'seesaw', 'stock market', etc. With the help of this question, one designer started categorizing patients: 'optimists', 'the ones force themselves to become optimists' and 'full pessimists'. Another designer, who highlighted 'life style' and 'a friend that is impossible to forget', expressed that she gained an understanding of diabetes as something penetrates patients' whole existence. One designer, who highlighted 'life', 'friend', 'children', and 'partner', expressed that she realized many patients described diabetes with words like that so 'it is like a part of their life'.

There was a noticeable tendency to associate diabetes with a person, such as 'partner', 'friend', 'sibling', 'naughty child', 'coach', 'enemy' etc. 'Personification' of diabetes allowed for its comprehension 'in terms of human motivations, characteristics and activities' (Lakoff and Johnson 1980, p.33). This tendency was observable throughout the survey answers: patients personified diabetes as someone they live with, interact with, who affect their lives, and who might have varying attitudes. The conceptual metaphor 'diabetes is a person' was very dominant in patient narratives; in most cases it was even more specific like, 'diabetes is an unavoidable friend'. Besides providing a specific way of thinking about diabetes, metaphors of diabetes provided with 'a way of acting toward it' (Lakoff and Johnson 1980, p.34).

When participant designers were translating metaphors used by patients into design ideas, the dominance of person metaphors of diabetes presumably inspired designers to incorporate personification in design ideas. Six out of ten designers articulated their utilization of personification in their idea generation processes. One designer stated that, since the time he had read this illness is a "life style" and it was advised 'to become friends with diabetes', he has been thinking of a companion and he further developed the companion idea into a design concept for diabetic children. Another participant designer, who highlighted 'First, you need to learn how to become your own pancreas', wrote the idea note 'not a pill but a new approach', and explained how she interpreted the utterance as follows:

'Here we can see a significant paradigm shift. Looking at your body from the perspective of an organ from your body... It can be translated to the product. 'What pancreas thinks when all these things are happening?', 'How would pancreas secrete insulin right know?'...

Same utterance inspired another designer to develop the concept 'pancreas buddy', a system that is always accompanying the diabetic children and would warn when necessary like, 'buddy, your blood sugar is low, let's eat a sugar cube'. One designer articulated the tendency about

personification and stated that the measurement device might have a personality, might even grow old with the patient. Mentor and 'life companion' functions were also discussed by several designers and it is stated that the feeling of a friend can be reflected in design. In all these articulations, we noticed that metaphorical expressions led designers to adopt a holistic conceptual approach.

While going through designers' ideas we observed that, utterances containing direct expressions mostly stimulated the generation of idea notes that fall into the categories of generating design criteria, improving existing products and developing new ideas/ concepts, whereas utterances containing metaphorical expressions predominantly led to the identification of possibilities and development of new ideas/ concepts with a holistic approach.

Additionally, participant designers also articulated the usefulness of metaphorical utterances. One designer pointed out the potential of metaphors, in her words, 'The positive metaphors of diabetes can be translated to design to bring a positive perspective'. Another designer stated that the answers of the question directed to obtain metaphors could be utilized while generating design concepts and marketing strategies.

Conclusion

To conclude, when patient narratives of diabetes were communicated to participant designers, on the whole designers directed their focus of attention to utterances conveying metaphorical expressions; and as exemplified by many cases these metaphorical contents facilitated idea generation process of design by providing deeper insights into users' understanding. Hearing about metaphors diabetes patients live by helped designers to see the world through the perspective of someone with diabetes; and interpretation of metaphors of illness resulted in a shift in designers' perspective towards more open, holistic approaches to design ideas.

Consequently, we propose that generating ways to engage with users through the use of metaphors can make significant contribution to user-centred design research, particularly when dealing with sensitive issues and in situations where designers have difficulties in empathizing with users.

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Data model design for eHealth services: two cases of modelling data sharing in chronic care

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ABSTRACT ONLY *With a growing population of people with a chronic healthcare condition, new policies including those of the WHO (2018), stress the importance of eHealth. So far, these services with advanced medical informatics technology offer increased possibilities of collecting and recording data such on for instance body measurements, treatment - and lifestyle activities (Wildevuur et al. 2015). However, the sharing of this data between patients and healthcare professionals is relatively unexplored (Heckemann et al. 2017).*

In this paper we interrogate meanings and assumptions relating to 'Design' and 'Technology' (Bate and Robert 2006; Reay et al. 2017), with a particular focus on the provocative term 'Design for Value' (Almquist et al. 2016; Ahmed et al. 2014; Bleich et al. 2009). We investigate the value of data-sharing in eHealth services for persons with a chronic condition. Our aim is to explore and model the data sharing in order to contribute to new experiences of value in technology enabled care services. The guiding research question: How to frame, shape and model personal data sharing with health professionals?

The research method builds on strategic design methodologies for co-designing care models for eHealth services. (Meeuwen et al. 2015; Oosterholt et al. 2017; Verhees et al. 2018). For this research we have crafted a data model design toolkit with enhanced visualizations of data exchange. The results presented in this paper include the data model designs for two cases of chronic eHealth services: A. Diabetes portal. B. Digital heart care journey. We conclude with a discussion on the modelling of data-sharing, its theoretical implications for the design for value and its further avenues for future research to deepen our understanding of data modelling and what designers and healthcare organizations can do.

Keywords: information for patients, information about medicines, animation, visual, quality assessment, Toulmin's argument layout.

Objects of desire and of disgust: Analysis and Design of Assistive Technologies

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ABSTRACT *Following the principle of 'one-size-fits-all', patients of different ages and socio-cultural backgrounds are often supplied with similar aids with little consideration for their personal preferences and socio-emotional needs. Assistive Technologies (ATs), specialist products for those with long and short-term conditions, are often being abandoned because of people's perception of themselves as disabled (Hocking 1999) and their fear of being stigmatized (Bright and Coventry 2013).*

A pilot study was conducted to explore how ATs may become 'Objects of desire' through design interventions, affording a more positive sense of self. This in return may increase the rate of adoption of ATs in everyday life.

ATs are often invested by more positive personal meaning when supporting independent living. However, the ATs market is very underdeveloped, and limits individual choice. While older adults are resigned to use available products that, at best, match functionalities in order to compensate for their occurring physical deficiencies, they express a wish for personalized, elegant, discreet and at times bold artefacts matching their lifestyle and providing opportunities for self-expression.

This study provides insights into the design language of medicalized products and the need to rethink the current approach.

Keywords: Assistive Technologies, Older Adults, Design for Desire

Introduction

'Assistive Technologies' (ATs) is an umbrella term that includes devices to increase or maintain the functional capabilities of individuals with injuries or declining abilities and to enhance overall wellbeing¹⁰. Studies on ATs (Lewin et al. 2010) suggest that a priority of older and disabled people is to live independently for as long as possible and to be engaged in social activities to reduce the risk of loneliness and isolation. Research conducted with 3000 participants aged over 40 years¹¹ identified key difficulties experienced, including getting out and about (23%), household chores (18%), DIY and gardening (11%), getting up from bed and getting ready for the day (9%), and preparing and cooking food (8%). As the world is ageing, the proportion of people who have difficulties with these activities of daily living (ADLs) is progressively increasing¹². In a recent report, Age UK¹³ stated that the percentage of people with at least one difficulty with an ADL increased from 16.4% when aged 65 years to around 50% over the age of 85 years. A wide range of independent living aids and products, many of which are relatively inexpensive, have therefore been designed to help improve people's health, safety and well-being (Consumer Focus 2010). However, in the UK, it is estimated more than 35% of ATs that are purchased are abandoned when they are still needed (Dawe 2006).

People are often supplied with standardized aids that tend to focus on the disability rather than the individual preferences and how physical needs change over time (Phillips and Zhao 1993). This has resulted in people who use ATs reporting an increased perception of themselves as disabled (Hocking 1999) and a fear of being stigmatized (Bright and Coventry 2013). These ATs whilst functional are rarely able to support complex rehabilitation trajectories as they are often not designed to evolve and are often rejected on the ground of aesthetics. There has also been less consideration about how ATs are in intimate proximity with the body and that they may be viewed as extensions of the embodied self. At the same time, these objects can be permeated with stigma and negative emotions, such as dependence, disability, and disgust. In this context, a sense of 'psychological contamination' (Rozin and Fallon 1987) may occur due to the proximity of an object that is stigmatized but also imbued with negative connotations and acts as public and visual reminder of a disability or of declining abilities when doing everyday activities. While older adults may resign themselves to use available products that, at best, match functionalities to compensate

10 <http://www.who.int/disabilities/technology/en/>

11 Previous Years Ahead, Silver, D. (2012) Less state, more self-funding: the changing face of the AT market in tough economic times. Design Ahead: design for an ageing population conference, 2nd March 2012, Bath, UK in <http://www.comodal.co.uk/Files/Comodal-Unlocking-the-Potential-of-the-Consumer-Report.pdf>

12 http://www.kica.care/wp-content/uploads/2017/02/The_Health_and_Care_of_Older_People_in_England_2016.pdf

13 Age UK and University of Exeter Medical School (2015); "The Age UK almanac of disease patterns in later life," - http://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/Age_UK_almanac_FINAL_9Oct15.pdf?dtrk=true

for their physical deficiencies, they also express a wish for more personalized, discreet and at times bold artefacts that are flexible to fit with changing physical abilities (Parette and Scherer 2004).

Narratives of medicine, decline, and functionality around ATs therefore remain predominant, with minimal changes towards narratives of consumerism, flexibility, and style. Our premise is that a shift in narratives and language around assistive technologies may improve their effective use, as well as the ambiance and emotional connection to ATs. This paper presents the methodology and preliminary findings from a pilot study that explores how ATs are perceived and to provide insights into how ATs may become 'objects of desire'.

The Pilot Study

The pilot study was qualitative and participatory in order to understand and explore the issues from the perspectives of younger and older adults who have used ATs in the short or long term or who may be potential users of ATs. Ethical approval for the pilot study was gained from Brunel University London. The research involved six focus groups – 4 with older adults and 2 with younger adults in order to compare and explore different perspectives of ATs across the life course. During each focus group, we aimed to explore the perspectives and emotions that the participants held when they envisioned the use of ATs by themselves or others, and to excavate how perceptions changed when the age of the ATs users changed (from young children to older adults).

13 British older adults (8 women and 5 men, ranging from 60 – 85 years old) were recruited through the Brunel Older People's Reference Group (BORG) and the Brunel University 50+ group from the Sports Centre took part, and 6 younger adults from Brunel University London (4 women and 2 men, ranging from 19-34 years old) also participated. Following a process of informed consent, ground rules for the activity were agreed, for example, consideration of all participants and for all discussions to remain confidential. Each focus group lasted between 70 to 90 minutes. To protect participants' anonymity and confidentiality names are fictitious.

The first part of the focus groups was dedicated to explore personal experiences and emotions encountered when using ATs. The activity was guided by displaying images portraying children, middle aged people and older adults using a wide range of mobility aids in the home environment, hospitals and in public areas. The second part of the focus group involved presenting the participants with a range of ATs which they could touch and interact with. The participants were asked to express thoughts and feelings around seven ATs namely, a pair of glasses, a hearing aid, a standard and a foldable walking cane, a wheelchair, a Zimmer frame, a motorized Scooter, and an Amazon Alexa (see figure 1). These ATs were chosen to explore a range of technologies and a variety of ATs that were highly visible, such as a Zimmer frame, and ATs that can be mostly hidden, such as a hearing aid.



Fig. 1 The seven prompts used in the focus groups divided for their visibility and level of technology embedded

A data-driven approach has guided a thematic analysis of transcripts with the intent to identify descriptive codes and to cluster them into main 'themes'. The appropriateness of each theme identified has been considered upon the recurrence of the theme across the data set and its relevance to answer the research question. The analysis stopped when data saturation was achieved.

Preliminary Analysis from the Pilot Study

Two macro-themes emerged from the transcripts; the first from the analysis of the first exercise highlighting differences in use and adoption of ATs as the user evolves, while the second derived from the interaction with the provided devices clarifying the participants priorities and preferences when purchasing and using ATs.

Functional customization of ATs

A view emerged that the role of ATs was to compensate for any loss of function and to limit the effect of deteriorating abilities across the life course. For some participants, despite needs for ATs, there was resistance in adopting ATs due to perceived negative connotations, for example, being seen as old: "my father wears hearing aids and he struggles because, I think, he is showing that he is old" or an increased sense of dependency: 'a Zimmer frame remind me when you are in a hospital and you are shuffling to the toilet' (both quotations from Sue, 61 years old). For most participants, the key parameters of ATs used in later life were functionality and product maintenance such as, 'the benefits [of using a device] overcome the visual disadvantages' (Sarah, 74 years old).

In contrast, when viewing the images of children, the functional dimensions of the mobility aids was interspersed with expressions of sadness for the children: 'it's good they've got them to go around' (Anna, 78 years old); for Louise (79 years old), 'you do feel sorry for the children but they [the devices] look stable, substantial'. Mike (76 years old) highlighted the possibility of enhancing their abilities as the children were growing up: 'the kid [using a mobility aid] might be learning to stand up straight, so you hold on to the frame so not to fall off, building up your strength [...]. I am assuming his legs were the problem but this [device] gives him the chance'.

Two emerging sentiments were elicited focusing on image of decline in later life and relation to the use of ATs by older adults and children, that focussed on the predominant image of decline in old age and of playfulness in childhood: 'there is pretty much a fun element [in devices for children] and when you are 90-year-old you don't want fun on your appliances...' (Sue, 61 years old). Mobility aids were often associated with playfulness as well as functionality for the children: 'I think they should be more fun...I was going to say they should be red and jolly and cheerful' (Vic, 73 years old). The younger adult participants also made a similar distinction. Laura (28 years old) said: 'I think they look independent and I think it's good even though all these devices are not children friendly, but they give a sense of independence which is good' and Jillian (30 years old): 'if it is something more playful and colourful they will think it is something they can have fun with instead of struggling with'.

In contrast, when viewing people in mid to later life, the mobility aids were described in relation to what extent the person could continue their everyday activities. Jillian said: 'they look very functional and people are able to do what they want to do, and they are given the opportunity to do their normal daily activities [...]. It gives a sense of normality - independence-'. Younger participants introduced the concept of functional customization of devices; Laura (28 years old) said: 'since [older adults] are stuck with these products for long it's good if they support multiple activities. If it is a frame like this [Zimmer] they can do grocery just adding a basket and a seat that can be removed if they want to go for a walk. Otherwise the frame would be too heavy. All these activities can be done with different frames and it is good for them to have options'; and Jillian (30 years old) added: 'like an extension pack they can put it on'. The narratives around older people therefore assumed a trajectory of decline and a need to do everyday tasks and activities in order to maintain independent living.

Permanent need for ATs and self-expression

A second theme that emerged from the exercise was the distinction between a permanent and a temporary need for a AT. If the need was viewed as temporary, participants expressed more acceptance of the ATs in their current design and function, for example, a standard, grey, metal walking cane was considered appropriate for orthopaedic rehabilitation from an operation or a fracture. Aesthetic concerns however were voiced more significantly when the need of an AT was permanent: for Sue (61 years old): 'if you see it [a standard walking cane] to a younger person you associate it to injury and you don't worry because is a temporary thing, as it was for my husband. With my father, he was a bit shinier [to use it] and you think he is at another stage of life [because

he needs it for a permanent condition]. It is a bit sad to see such a strong and fit man to depend on a stick and you don't think is a temporary thing'.

The permanence of the AT was not always associated with decline, but also to narrative of athleticism and sport, in particular the role of the Paralympics. As Sue said: 'I think is the association with sports...and Paralympic games...there is a new feeling... you feel very positive because you see this engineered frame [as an advanced design] and you are positive for future generations. New generations are embracing new prosthetic limbs and technologies'. The Paralympics was therefore seen as having brought to wide attention novel possibilities of design that could be personalized, flexible and customized for the user. The purpose, design and context of ATs was therefore significant. For example, whilst a standardized walking stick may be stigmatized, contemporary designs and activities are promoting new aesthetic dimensions: 'there was a period where gentleman used sticks [...] - now we have trekkers with this Nordic style and I think that's the way they will become' (Marta, aged 60 years). As Marta further explained: being "trendy and young" was what made the difference.

Some ATs that are taken for granted, with less stigmatization, in particular, glasses as a means to enhance vision were 'normalized' (Nas, aged 26 years). The extent to which an AT was not very noticeable, often due its size and close proximity to the body was also important. When an AT was less visible, there were, however, contrasting ideas; for example, Lucy (aged 34 years) said she preferred it when assistive devices, especially hearing aids, were invisible, as they are not as commonly used as glasses, and may be stigmatized. Nas introduced a more positive concept of 'cherishing the disability', by making devices fancier, visible, desirable. What made devices aesthetically less accepted was seen as 'the scale of the market' (Laura 28 years old) and because 'we don't see them around' (Bob, 34 years old).

Participants on the whole agreed that technology could be an effective enabler to enhance human activities and there were possibilities that ATs may be imbued with positive connotations, as representations of the individual's dignity and self-respect, and by nurturing the functioning abilities of the user. However, if devices were seen to merely replace an activity that users could do for themselves, such as, the use of a scooter in large shopping malls or in holiday resorts and asking Amazon Alexa to do everyday activities, they were often associated with laziness by many participants, both younger and older, and therefore not always seen as useful for purposeful living.

Conclusions

The diffusion of ATs and the emerging use of consumer technologies for assistive purposes, has brought up a wide set of concerns and desires beyond the mere functionality of the product. The consumer products' market provides a great degree of choice to consumers; this is to cater for individual preferences, tastes, levels of usage, and personal requirements. The same choice does not extend to assistive products even though they are becoming increasingly prevalent for longer periods of time as we live longer. This is of significant concern as lack of choice may impact the adoption rate of assistive technologies. In the case of mobility aids the lack of adoption may result

in falls, limited mobility and less engagement with social activities, that may compromise overall wellbeing. As for consumer products, older adults would like their choice to reflect their identities and as a form of self-expression. Therefore, in order to counteract the one-size-fits-all design of assistive aids towards a 'humanized' technology support, our preliminary findings suggest that functional customization, by means of personalization that allow products' changes so as to have multiple purposes and functions, can reflect the complex disability management of the users. A second theme emerged when assistive devices are seen as permanent and become central to the user's life and a bodily extension. The aesthetic importance of the device in terms of self-expression, with increased social acceptance, was considered significant. When devices embrace technical and futuristic features that empower the user, they are more likely to be enthusiastically accepted which has the potential to improve everyday life.

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Speculative futures: Health at home now to 2040

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ABSTRACT ONLY *The community care sector is going through significant change in Australia, it is being impacted by the rapidly growing aging population (Australian Bureau of Statistics 2015; Productivity Commission 2015), emerging technologies, changes in government funding and disruptions on the market (National Disability Insurance Scheme reform). Healthcare providers and businesses need to embrace the change and create new opportunities for the growing number of people requiring access to community care services. We are interested in how community-based care will change in the coming decades. We see design as a powerful tool to research and inspire fresh new approaches to the co-creation and implementation of social services with communities. For that reason, we have begun designing artefacts that reflect forward what we have learnt through contextual enquiry, cultural probes and ideation sessions. Our final results are visual designs, speculative objects and storyboard scenarios showcasing immediate and far-future design interventions—from now to 2040—to imagine alternatives, prepare for the future, shape it; and ultimately be less afraid*

Keywords: human-centred design, qualitative research, co-design, contextual enquiry, design artefacts, speculative design, futures, technology

Tactile toolkit for mental health conversations

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ABSTRACT: *Globally there is an increasing business focus on creating workplaces that support employee mental health and wellbeing. Researchers estimate that at any time in Australia, 1 in 5 working age people will be suffering from a diagnosable mental health disorder, with another 1 in 5 suffering from other mental health issues like worry, fatigue, sleep problems (Australian Bureau of Statistics 2009).*

We design facilitate co-design activities in our practice to host conversations with individuals, teams and communities around sensitive topics from homelessness to expectations of crisis support services. The tools we create promote self-reflection, empathy and create spaces for people to share things that are often difficult to verbalise or express. Recently we have been prototyping new approaches to support challenging workplace conversations in an inclusive and generative way.

We would like the opportunity to showcase and test our tactile toolkit prototypes at Design4Health 2018. Driven visual and auditory prompts the toolkits help participants express thoughts and experiences by selecting—found and designed—ambiguous physical stimuli to share personal stories. The shapes and textures act as prompts for rich conversations about mental health and wellbeing at work. Built on the work of MakeTools this approach provides opportunities for creativity, expression and discussion (Sanders and Stappers 2014) across various scenarios. The flow of the conversation and use of the tool allows participants to explore mental health topics while building empathy with each other, this is seen as the first step toward creating an action plan at work.

Keywords: MakeTools, conversation starters, co-design, toolkit, mental health, inclusion, tactile design

Experiment 1: Co-design toolkits in workshops

We began developing co-design kits at Today a few years ago in order to help workshop participants express themselves quickly and concisely during prototyping workshops. The co-design collage kits contained a selection of deliberately ambiguous visual stimuli to be used for brainstorming and storytelling activities. Based on the premise of generative design these kits combined the action of collage with the theory of cognitive mapping. By having simple, movable elements the kits goal was to help participants get their thoughts down without having to worry about all of the details or feeling they had to get the composition 'right' the first time. Our aim around the toolkits was to help people concentrate on the flow of ideas and to iterate quickly, and to drive home the point that all of us can design with intent—even though we might not be able to sketch or write.



Figure 1 Co-design toolkit (centre) and a Tactile kit version 1 (right) being used to help entrepreneurs, students and faculty to design prototypes.

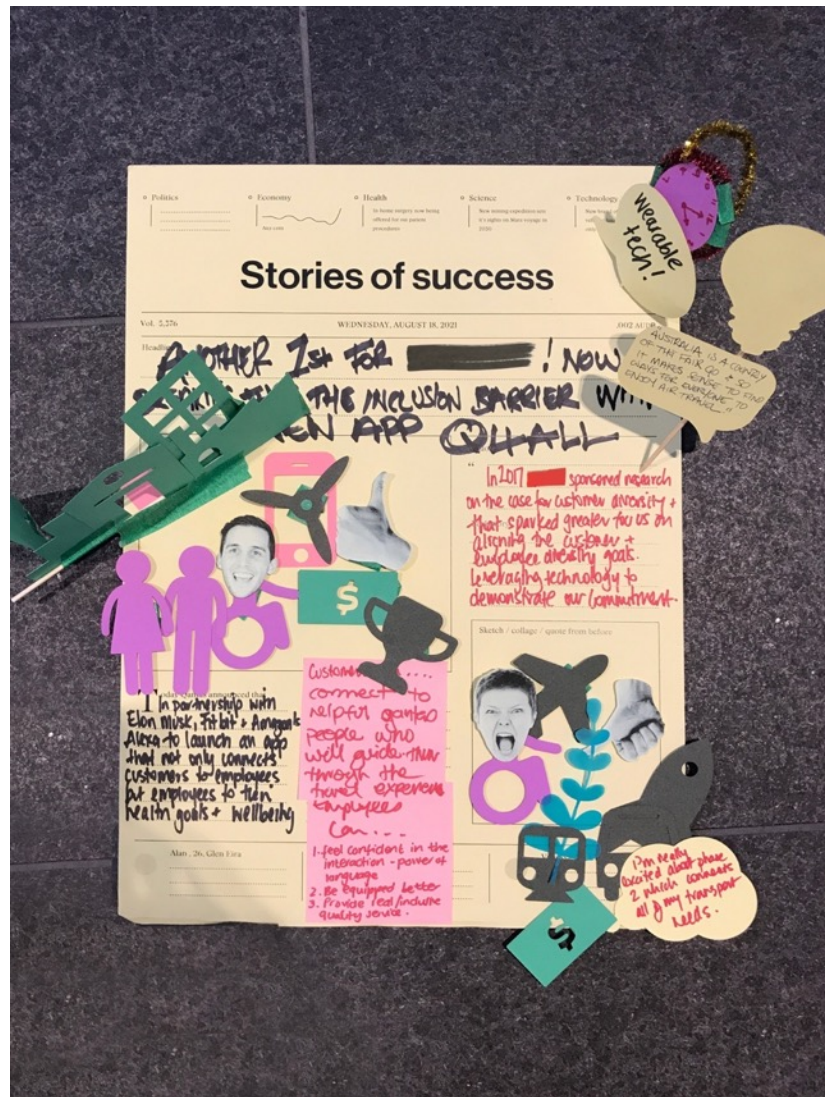


Figure 2 Example of a 'Tomorrows headline' created using the Co-design toolkit, this was used in a workshop setting with participants with disabilities.

Results: The co-design kit was flexible enough to be used in a variety of ways and accessible for people who might not otherwise participate fully

The co-design kit elements did require refinement and curation over the last year, which is something we have been able to do through iteration. Despite being imperfect the kit itself gave participants plenty of room for creativity in expressing current experiences and ideas and in generating new ideas or future visions. The ambiguity and the visual nature of the kits started great conversations among participants and gave us as a researcher richer sources of information than a filled in worksheet or post it notes on butcher's paper. We also observed during sessions that the kit shifted dynamics slightly with people able to participate regardless of age or ability.

The toolkits, even in their simplest form had the bonus quality of adding play into the act of mapping some quite serious challenges. Two distinct behaviours we identified when using these kits that we wanted to explore further were:

1. how this kit was opening lines of communication and
2. if the kits were encouraging a more flexible thought process by giving people stimuli they could interpret themselves.

The last 18 months have seen the collage kits used successfully in twenty different settings including:

- Conferences to prototype future government services with public servants
- Lean prototyping training with entrepreneurs and universities
- 1:1 interviews to capture existing emergency housing experiences with youth who are experiencing homelessness
- Sessions to build narratives of domestic violence experiences with victim survivors
- Workplace co-design workshops to ideate ways to remove barriers to participation with people with disabilities
- Start conversations among experts around sexual harassment and discrimination in Victorian workplaces

Experiment 2: Tactile toolkits to start conversations

In our workplace we are increasingly working in the mental health space and with people who are diverse, both culturally and linguistically diverse (CALD) and with diverse ability levels.

Accessibility has become a real issue for us as we struggle to use traditional worksheets and templated activities to capture information in an equal and inclusive way. To address those two challenges, we turned our attention to creating tactile tools and prompts. We focused our toolkits to create tools (objects, activities and scripts) that could help two individuals speak in depth on a topic that might be challenging or awkward. Initially we trialled our tools in group settings and workshops, but we found the tools to work best between two individuals, so on-on-one.



Figure 2 Version 1 Tactile kit elements include items that are natural and synthetic, warm and cool to touch, have elements that can record sound or emit light.

After discovering the tactile toolkit worked better as a classic interview or dyadic group we started to design a baseline conversation between two or three participants using the kit. We based this conversation script on how we might run an interview with a research participant, mapping our questions for participants along 'The Shape of An Interview' (d.school, 2013). The script had had an introduction to the tool, an icebreaker, 2-3 contextual questions, 2 deep questions, points of clarifications and closing. The script was printed or presented on an iPad to be used with a screen reader for participants to navigate together.

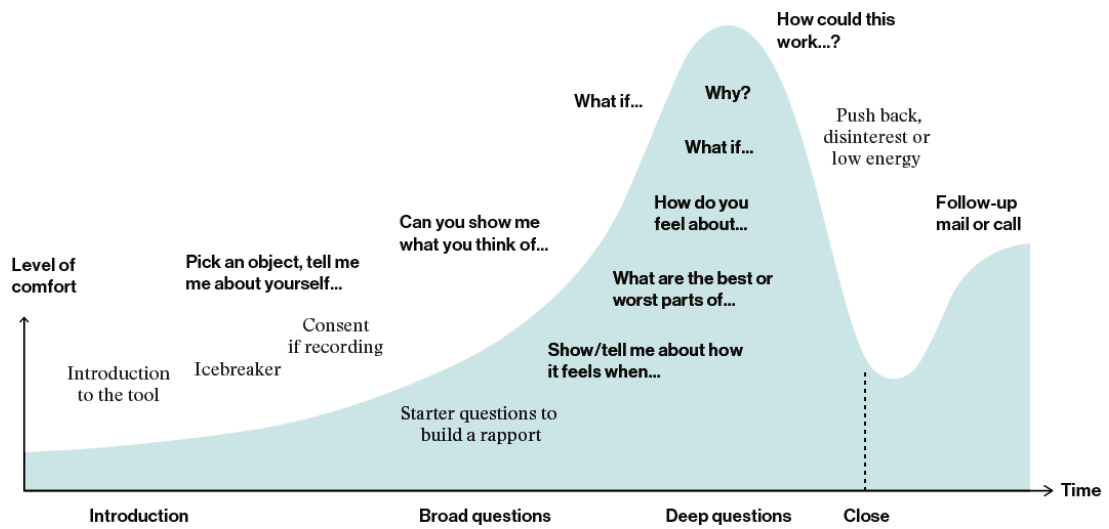


Figure 3 High-level diagram of our conversation flow using the tactile kit



Figure 4 Version 3 Tactile kit elements include items that are malleable and increasingly ambiguous. Participants appear to read more into shapes that are uncommon or undefined.

Results: The tactile kit didn't work as well for prototyping, but it did work well in assisting conversations and reflection

Starting by collecting household objects the first version of the tactile kit was used in a workshop setting. The kit was given to participants like the co-design toolkit was in past experiments. Its goal was to assist people in designing future experiences and services. We observed during group brainstorming sessions the tactile kit was overwhelming. We believe that by not having as many familiar symbols and shapes the tactile kit made creating a prototype difficult to. Participants appeared to hesitate when selecting a tactile object, the process of design was slower than the more symbolic co-design kits we had made before.

The tactile kit did however, come into its own when used as a reflective prompt. People could easily touch, combine and select items when given questions around how an experience felt or should feel. Currently we are using the second version of the kit as an icebreaker to sessions. Breaking up into pairs we allow participants and interviewees to take a few moments and select objects that ‘feel like the service has felt’ or ‘feel like the service should feel in the future. So far, we have tested this activity with forty people of diverse backgrounds and with disabilities with promising results. We suspect that this moment of reflection has given us a strong grounding during group sessions and provided us honest and insightful answers from the start of a session.



Figure 5 Tactile kit being used in a workshop icebreaker between a designer and a participant with low vision. The question asked was “Pick an object that describes what art is like to you”.

Next steps for the tactile toolkit are to explore conversational interfaces

We continue to work in the space of the tactile toolkit exploring the role of physical objects in supporting reflection and dialog between people. In particular we are concentrating on creating kits that assist employees and employers have challenging conversations around mental health at work. While experimenting in this space we are taking steps to ensure that our kit is accessible to all and able to scale. There are two steps to this project which we intend to investigate for September:

Step 1. To refine our mental health interview and activities with professionals so we can prototype it using conversational interfaces. This means creating a script, basic interactions and instructions for participants in the conversation. The goal of this is to be able to test the tool and conversation quality remotely without a researcher present.

Step 2. If the testing of the conversational delivery is successful and the activities are clear and stand-alone, then we will begin to build a simple online tool to deliver our mental health conversations. While the first tests may be 'smoke and mirrors' at this stage we will pilot if the combined software and a tactile kit can deliver a conversation well.

Conclusion

Generative toolkits and *Maketools* are known by designers as way to elicit creativity, expression and start discussions between research participants. These tools and approaches are not widely known outside the realm of design—particularly service design— and have untapped potential in the testing and improvement of health services. Our experiments to date show that tactile tools when paired with scripts and conversation starters work well to facilitate deep conversations. The future of these conversational tools is exciting, as they have the potential to be designed for accessibility and improve services. At this stage our research is still at an early stage, we will continue to refine our designs both as tactile elements and scripts with the goal of being able to deliver conversations remotely and online.

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Co-designing time to chat, to reflect, to get it right: Young designers learn from older adults co-creating toolkits for peer-to-peer information sessions.

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Priday and Jeanie Beh**

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ABSTRACT *Staying active later in life is considered important for our health. Government bodies create programs encouraging seniors to remain active and independent for maintaining quality of life. Typically, councils engage design studios to design active ageing programs where the designer/client interaction is paramount. Interest in co-designing with rather than for end-users is growing, yet some claim it takes too long or does not lead to the desired results. This is also a challenge when included in a one semester university course for design students. This study aimed to find out what happens when taking the time to co-design. Strategies were co-created across two cases with two local councils briefing the students on 1) personalized active ageing plans and 2) navigating the aged care system. Three co-design workshops were held with 22 seniors and 26 Master of Design students from an Australian university, over 12 weeks with time for design, analysis and reflection. The findings show mutual surprise from the design students and the older adults as they share stories from their own perspectives. First, the design students reflected on how time needs to be negotiated in co-design when older adults enjoy taking their time and chat and young designers are under time pressure. Second, the design students were surprised that it was these unplanned conversations that led to design ideas. The older adults were surprised at the effort invested in the co-design activities for them and how thought provoking and fun the activities were. We argue co-designing independent ageing solutions with designers and seniors is indeed a good investment of time. We conclude that also allowing the space for storytelling, and reflection, leads to empathy and mutual learning for young designers to understand older adults and for robust design responses to emerge.*

Keywords: Co-design, design education, ageing-well, participatory design

Introduction

Remaining independent and healthy and making choices to live in one's own home for as long as possible is not an option anymore, it is an important part of the Australian Government and local council's agenda. Much information resources aim to support older adults plan for active aging and their own aged care. However, these resources - often Websites - are often fragmented, and difficult to navigate. Partly older adults do not know where to start, are unaware of available resources or avoid the topics around ageing altogether. This paper presents two cases with local council briefs: (1) Planning for aged care and navigating the aged care system and (2) active ageing which includes a range of offers such as creative, learning, and physical activities. Students were challenged to co-design toolkits for peer-to-peer sessions on individual active ageing and aged-care strategies. Similarities were to find out about older adults' information needs and tools necessary to achieve these needs. Peer-to-peer support services are seen as one option to help people to access the right information and point to relevant resources. Research shows that peer educator programs leads to an increase in health literacy and health benefits, but their overall effectiveness is inconclusive (Peel and Warburton 2009; Seymour et al 2011). One early study suggests that the peer education model was providing nutrition information to a broader sector of the senior population than public health promotion (Lynde 1992). Reports on My Aged Care system recommend to explore peer-to-peer support to ensure people get support to navigate a complex system and achieve consumer directed care (Elliott et al. 2016). While research provides a positive picture of peer education models - in particular in breaking down communication barriers, reaching marginalized groups and being sustainable - it is critical to provide training and support to the volunteers (Peel and Warburton 2009). We suggest that tools to support volunteers in their role as peer educators needs careful consideration. Volunteers need to be equipped with the right toolkits to be able to inspire their peers to be actively engaged in their personal health. We believe co-design is a promising approach to create these types of toolkits.

Co-design is a design process, where all stakeholder are included in the design process to ensure user needs are met (Taffe 2015). The role of the user is no longer 'user as subject', but being in partnership with the designer (Sanders and Stappers 2008, p.1). Co-design is beneficial for designers, giving unique insights into user needs and preferences. The concept of co-designing with end-users can be challenging for both designers and end-users. However, when it is carefully organized and implemented, co-design workshops can result in a sustainable outcome and enhance quality of life (Sanders and Stappers 2008).

Study aims

Aged care project: The aim was to assist people needing aged care support to make informed choices about their future and to provide a trusted source of information, provided by people with empathy for the person's situation and unconstrained by bureaucratic requirements.

Active ageing project: Besides the objective to provide information on health and wellbeing opportunities for older adults one aim was to increase the digital literacy of seniors for them to access an online hub. This hub is key to finding suitable local health and wellbeing information.

Both projects aim to (i) convey information on independent ageing and future planning, (ii) maintain an active lifestyle for the older person, (iii) tailor the mass of services offered into a personal journey and (iv) use peer-to-peer sessions to achieve these goals. While co-design is commonly used as a process to create appropriate solutions, in our study the final co-design activities constitute the solution to create the individual active ageing/aged care plans in the peer-to-peer sessions.

Co-design activities

The design students involved were from diverse discipline backgrounds including communication digital media, interior, and product design in mixed-disciplined groups of 3-5 students to create the following:

- Co-design toolkits to attract and engage older adults.
- Space designs for the sessions
- Branding the volunteer peer-to-peer program.

In total there were 26 students in 8 teams. Here we report on the outcomes of two teams. Across the workshops the students co-designed with 22 older adults – a combination of older adults from the community, future peer-to-peer volunteers and members of an ageing committee.

Students started to create motivational models with functional, quality and emotional goals based on the approach of Sterling and Taveter (2009) extended by Marshall (2014). They predicted what the final solution should 'do', how it should 'be' and make users 'feel'. These prioritized goal tables were the basis for creating co-design activities. For example goals for the aged care domain included 'provide clear information', 'be supportive', 'feel comfortable'. Figure 1 shows the co-design process followed by the students.

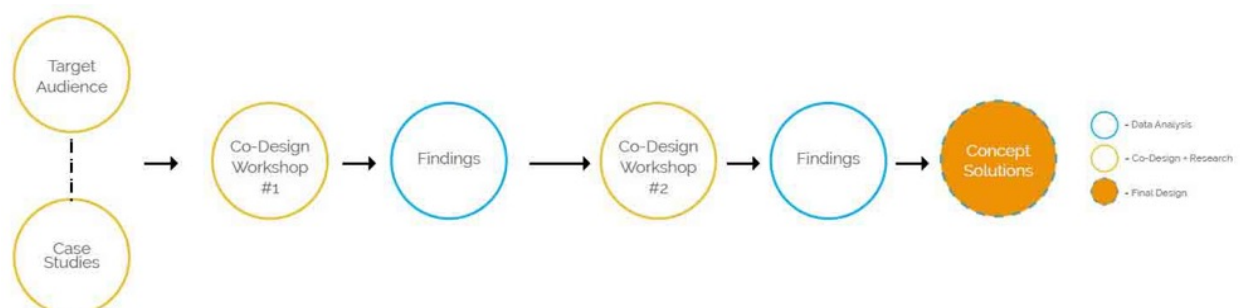


Figure 1. Co-design process [student report 2]

Workshop one took place in a university classroom. As the prospective peer-to-peer sessions were to take place in libraries and neighbourhood houses the second workshops were held in the local

library and in a council community centre. The final reflections and presentations took place at the university.

Aged-care team

Co-design Workshop 1. The materials included an ‘information session invitation’ worksheet to identify key problems people have navigating the aged care system. The students decided ‘it would get people thinking about what they wanted most from the service, conversing about issues and create useful information artefacts in the process’ [student report 1]. Another activity concerned information sources (e.g. internet versus phone).

Student Reflections on Outcomes. Responses were concerning trust and unscrupulous operators who seek to take advantage of elderly people. This suggests that trustworthiness and honesty needs to be a design consideration. Another response concerned the fragmented information from different sources (figure 2). Overall participants were savvy to use the internet, but it was not always their first preference. They explained that a phone call can be more efficient than internet searches as it navigates complexity. A weakness in the activities was not enough consideration of participants who knew nothing about the aged care system, thus making it difficult for them to engage.



Figure 2. Participants filling in a worksheet on their desired information session on aged care

Time was an issue for people wanting to share their experiences. Overall the activity was versatile creating rich conversations but could have been more fun. One student commented:

‘I was happy with my activity because it encouraged people to think and come up with ideas about problems and how to reach people and not just ask them about their preferences. [...] A gentleman thanked me afterwards [...] he felt he was actually involved in co-design and not just doing a random task.’ [Student report 1]

Co-design Workshop 2. Based on these results the team focused on supporting people obtain a Home Care Package. An opportunity was to incorporate different circumstances and how people feel at various stages of the process into a design solution that could identify and encourage

support when it is most needed as well as inform. The aim was to create something where people would feel less 'lost' and more 'comfortable' and 'trusting' in the process. Journey Mapping is often used to understand how customers interact with services whilst accomplishing a goal (Rosenbaum et al 2017). Here it was important to capture segments in the journey where people encounter stress to consider adding more support. To do this the students incorporated basic empathy mapping using written comments and emoticons to get feedback on how older adults feel and what they would do as they progressed through the journeys' stages.



Figure 3. Simplified Journey Map for Home Care Package & work sheet to capture results [student report 1]

Final Design Concept. The idea started as a simple journey map to assist users but developed into a prototype for the volunteers and older adults to be used in the peer-to-peer session as it proved to be effective, identifying the difficult stages of the process. The conversations prompted by the map proved to be the most important. The final kit includes simplified user co-design activity materials as well as a detailed Home Care Package Journey Map template (figure 4) designed to guide the conversation and a leaflet for the person to take home as a record of the session.

Home Care Package Journey Map



Sarah is the daughter and sole carer of her 89 year old mother who is beginning to have difficulty around the home. She works full time, has two children of her own and lives an hours drive away so finding time to make sure her mother is well and has everything she needs can be a struggle. Her mother recently had a bad fall whilst doing the laundry, and they have both decided that they are ready to find some in-home support to make life a little bit easier for the both of them.

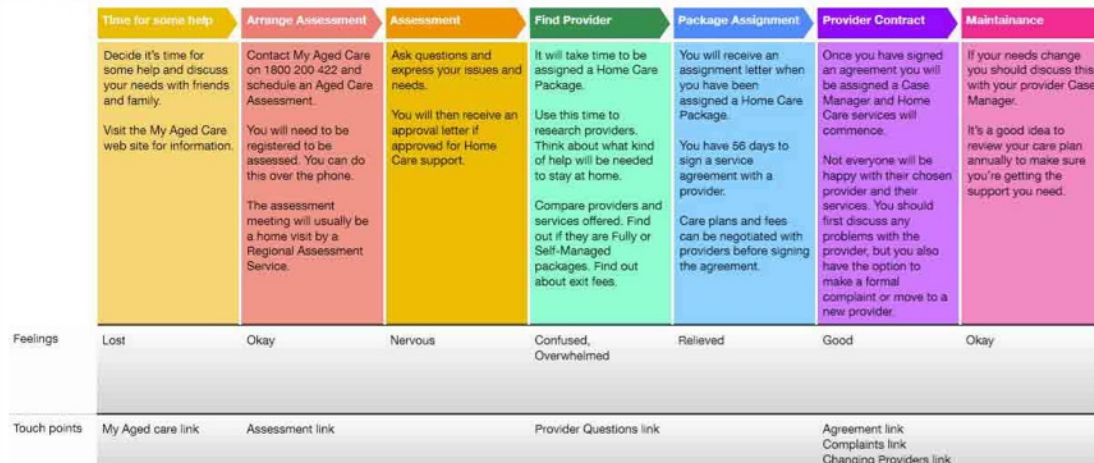


Figure 4. Prototype for Home Care Package Journey Map [student report 1]

Active ageing team

Co-design Workshop 1. One co-design activity called 'the three monkeys', invited participants to be immersed in being deaf, blind or mute to understand how information is conveyed in different scenarios. Three participants took part to pass along a 'message'. Participant one (blindfolded) described an object to participant two (wearing a face mask), acting out to participant three to guess while listening to music (figure 5).



Figure 5. Three monkeys exercise

Student Reflections on Outcomes. The older generation seemed more comfortable learning exactly what needs to be done first before jumping to conclusions and were also patient and precise giving or receiving instructions - careful to not make any 'errors'. This helped in giving conclusive data on two aspects - the method in which ageing individuals receive and interpret

data is more composed and precise and the fact that peer-to-peer education is indeed a good idea as communication between peers seemed to take place more efficiently.

Co-design Workshop 2. The purpose of this tool was to attract people and their attention to a set of games (memory games, Rubik's cube, mini golf) in order to deliver information about active ageing (figure 6).



Figure 6. Game activities to engage people

Final Design Concept. The final solution can be divided into two sections (i) attracting and engaging with the audience via spatial design and branding and (ii) providing and collecting information via a weekly preference and planning sheet. The branding 'hello' was designed around council guidelines. The colours provide an energetic and positive vibe symbolising action and activity. The brand is used to announce the existence and relevance of the active ageing initiative and ways to participate, accompanied with fun activities, promising a pleasurable engagement.

Designing the space for the interaction is key. The space needed to be quickly and easily constructed, deconstructed and re-constructed. This was achieved through its modular structure.

The 'calendar' is an interactive tool which can be used by volunteers to understand individual older adults. A colour index symbolises the different categories of activities offered by the council. The volunteers ask participants to fill in the calendar with colours based on their activity preference on each day of the week. Based on this information, the volunteers can help tailor individual monthly or weekly schedules and point to the respective sections on the ageing website.

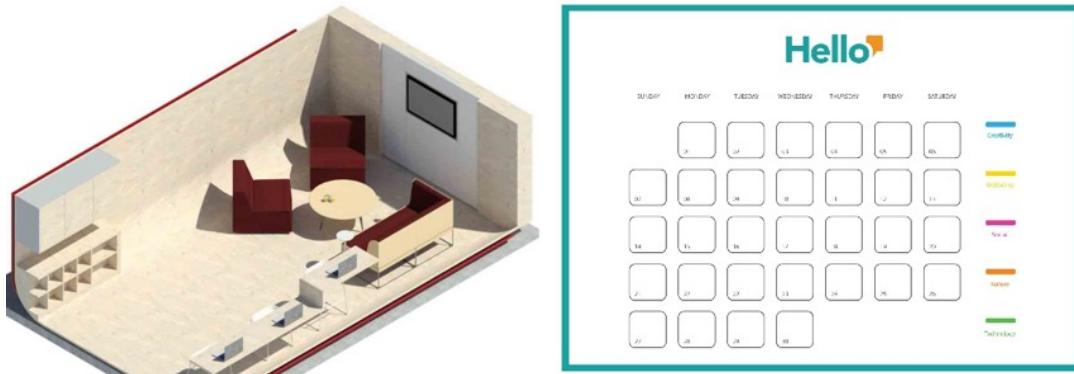


Figure 7. Suggested space and branded calendar [student report 2]

Findings

Older adults' perspective. Overall the older adults enjoyed the interactions with students. In particular in the active ageing activities they played along although they did not always understand the purpose of the activities. They appreciated their invitation to be involved and the effort taken by the designers creating all these materials 'for only one session'.

Students' perspective. The main theme was finding the balance between time management and talking to the older participants. Time was on the one hand seen as a challenge: Timely set up as older participants tend to arrive early, keeping activities brief, not knowing how long activities take due lack of practice or inexperience and getting succinct information from the participants were common themes. However, where activities extended to longer conversations both students and older participants enjoyed these and it was then when the biggest insights were gained and empathy built. Hence some wished for more time to be planned in. Some of the student comments from the feedback questionnaires emphasise this:

I enjoyed chatting to some of the participants. I really felt and shared their frustrations about the aged care system and got a better picture of some issues. [...] They wanted an opportunity to talk.

I think better outcomes really can be achieved by better awareness, understanding of the system and sorting things out before crisis. I'd like to help somehow.

...more time. So, people don't feel rushed, or worse interrupted when they're expressing experiences, thoughts and ideas.

I really didn't want to ask them things only then to not to let them finish what they have to say, or not let them finish their activity

Some students working with ageing committee members felt that this was not the right group for the co-design activity. While older adults themselves they did not seem to feel this topic was relevant for them and expected complete 'solutions instead of activities', which emphasizes again how important it is to carefully choose co-design participants, to manage expectations upfront, but also develop resilience in the innovative space. Overall students were surprised by: how much they learnt, the openness of the participants and how the process informed their solutions. They saw the co-design as crucial part of it. The learning included overcoming prejudices in regards to older adults and technology use, breadth of opinions and how a single incident can be life changing (e.g. a broken leg).

Conclusions

Students co-created toolkits for two local councils based around the peer education model. They trialled the peer support toolkit several times and refined it based on older adults' needs and preferences. Co-design approach allowed time and space to motivate conversations. The co-created tools indeed were suitable for conversations – first as icebreakers, but also to explore preferences, build empathy and generate new ideas. Participants admired the students design skills, interest in the aging topic and investment of creating rich co-design materials. While the students were stand-ins for the future peer-to-peer educators, older participants particularly loved the intergenerational interactions and longer conversations. It was then when stereotypes were overcome in regards to perceptions about technology and ageing and unexpected things were learnt which sparked design ideas. We propose to plan for extended time commitment that leaves space between activities to talk seeing co-design activities as conversation starters allowing the complex issues around ageing to unfold. Two examples demonstrated that students devised solutions to tailor in a co-creative conversation the mass of service offers into a personal health journey. The design students also learnt that innovation processes need openness and a certain degree of resilience. In accordance with Sanders and Stappers (2008), we suggest that participants need to be chosen to exactly match future users and activities prepared and explained carefully so all involved understand their roles and benefits.

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Playful technology to help deaf children to speak: A case study using co-design method for designers to learn from speech therapists and parents

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ABSTRACT Every year approximately 500 babies are born deaf or hearing impaired in Australia. After a cochlear implant, young children can learn to speak with intensive speech therapy. A range of paper-based speech therapy programs exist, but there are few technology-based programs. The benefits of using technology to practice speech drills for busy parents is compelling, however there are few such tools for parents to use. This paper presents a case study questioning what design elements are appropriate for a speech therapy iPad application for parents of young children. Speech therapists and carers of young children were invited to co-design an iPad application with 15 Master of Design students from an Australian University. Two workshops trialled a variety of co-design activities, over a 12-week period to allow time for reflection and design prototyping. Case study method was used where a rich description of the context, co-design activities and findings were coded and analysed for common themes. When designing an educational iPad speech application for young children, the co-design process highlighted the following important requirements: (i) design for play rather than learning, (ii) gradual exposure to the application not to block interest, (iii) use a variety of imagery (dogs as the preferred animal), (iv) use popular culture cartoons and images, (v) develop lip reading as well as sign language games, (vi) allow space for getting it wrong while playing, (vii) design for privacy and personalized settings, (viii) send the young child's learning progress to parents and speech therapists, (ix) design aged appropriate levels, and (x) focus on parents as role models for speech learning. We conclude co-design is useful for uncovering appropriate design elements when the activities are playful, colourful, and hands-on. When co-design activities ask indirect questions of the participants, a rich picture of the context emerges.

Keywords: co-design, participatory design, education, human-centred learning

Introduction

Speech development is a major milestone in every child's development. It starts from the first utterances of sounds and cries when babies learn to communicate with their carers. Delays in speech development are known to be responsible for a range of associated problems in an individual's overall psychological and cognitive development (McLaughlin 2011). These problems include language disorder, behavioural and socialization difficulties in school, and intellectual disability (Law, Garrett, and Nye 2004; Law, Boyle, Harris, Harkness, and Nye 1998; McLaughlin 2011).

Due to these consequences, hearing impairment of children needs to be addressed as early as possible. In the United States alone, there are approximately 10,000 infants born deaf every year (Mellon et al. 2015). Hearing impairment is also of large concern in Australia where approximately 500 hearing impaired and deaf children born each year. Much of the responsibility for addressing the problems of hearing impaired children is handled by parents (King 2006). Parents however, struggle to find solutions to helping their child practice speech therapy exercises and are constantly looking for the best communications and educational methods to use within the family environment. To date the main reliance has been on paper-based resources such as early language learning books and children's story books. While a number of these are known to be effective (e.g. Hagen, Pellom, and Cole 2003), little research has gone into developing and monitoring the potential benefits of technology-based solutions in this area.

Great advancement has been brought in hearing impairment technology with Cochlear implants. However, technology advancements are just the beginning as children with Cochlear implants need intensive therapy for speech development to meet the levels of hearing children. Technological practices developed to assist the speech development for children born deaf with Cochlear Implants are lacking and are poorly understood. Parents are typically strongly engaged in and play a major role in the development of their children's speech learning processes (Rice 2012; King 2006). Hence, the existing practices besides therapy sessions with pathologists include toolkits for parents to teach their born deaf children at home that require long hours of parent-child exercising everyday. Consequently, there is a need for technology tools that can be used by the children self-directed to free up time for parents to do other duties. To be engaging for children there is an opportunity for graphic designers to fill this gap in developing speech assistive technology-based tools to help parents teach their born deaf children to speak through appealing graphics and interaction mechanisms.

Interaction with digital games is known to have strong positive effects on children's learning generally (Huber et al. 2016). These facts lead to a conclusion where designing an interactive digital game on an iPad application could assist in speech learning development of children born deaf.

Methods and materials

Co-design, involving facilitating input into the design processes by those who will use a design, is a growing area of interest for designers (Sanders and Stappers 2008; Taffe 2015). Co-design case study was chosen as the method for parents of young children to give their insight in the design process of engaging digital games to support speech development. The following co-design case study took place in an Australian university with an established Master of Design program (60 students enrolled in two-year coursework building on their four-year Bachelor of Design degrees from overseas universities). The study took place in a unit, called 'inclusive and participatory design'.

A senior lecture at the university (a specialist in media and communication) had the vision for the development of technology-based iPad app after her daughter was born partially deaf and experiencing the intense speech therapy program required. She briefed the masters' students on the need for a playful game to assist deaf children's speech learning, challenging the students to design an interactive solution to engage children and parents in the speech learning process. A team of lecturers taught the students the latest theory and practice on co-design principles, where designers work *with* end-users rather than *for* them, co-creating outcomes together, suiting end-user's needs and preferences. Two speech therapists, five parents, five design academics and 16 multi-discipline design masters' students took part in two workshops divided into 4 teams of 4 students. The students devised a range of co-design activities to trial at the workshops. Figure 1 shows an example of the prototype games used as interaction prompts in the workshops. The four co-design games were:

1. *Chirp It* focuses on making each game interactive, fun, informative and challenging for the participants.
2. *Clumsy Joey* tells a story about a clumsy and friendly baby kangaroo who needs the children's help to find his things.
3. *Storyland* involved the participants in a story scenario related to speech and language acquisition.
4. *The Adventure of Maggie The Monkey* is a prototype tool to allow participants to learn about basic words with rhyming through songs and word repetition.



Figure 1. Clumsy Joey co-design toolkit designed by Master of design students

(Author photos of workshops 2018)

The students followed a process of developing and refining co-design toolkits to meet the needs and preferences of the end-users with several weeks in between for reflection, based on their findings and feedback from the co-design workshops. All participants completed a reflection questionnaire after each workshop and the design students were interviewed to share their experiences from their twelve weeks of study.

Findings

The findings from the two co-design workshops by the design students will eventually form the basis of the design recommendations to be developed further into a speech learning game. The four prototype games are as follows 1) Chirp It concept helps the speech learning development with interactive games between parents and children, with the use of learning basic sign language; 2) Clumsy Joey expressing the interest of children by creating a finding items game with a clumsy character to engage with the children; 3) Storyland approaches the needs of children from multicultural background with the perspective of various language used in the story with themes; 4) The Adventure of Maggie The Monkey solves the speech learning through rhymes, songs, and appealing character.

Chirp It

Chirp It toolkit aimed to improve the bond of parents and children while playing speech learning games. Each word selected in the game was categorized as per the co-design toolkit. The words

are split into categories of different environments, making it easier for the child to understand. The participants were asked to play three games, 1) Guess It; 2) Say It; and 3) Sign It (Figure 2). While one child played together with his mother, he was able to learn to give clues through acting with his body, learn lip reading and choose the right item prompted by the game, and learn the basic AUSLAN (Australian Sign Language). Through this activity, the designer understood that sign language was found to be very informative and helpful for young children to learn before they learn how to speak. Each participant was intrigued to learn sign language. They found out that a guessing game is highly interactive and fun, it creates an interaction between two players and allow parents to be involved in the children's speech learning process. The lip-reading game also came across as a challenging game. In response to this, the students created an iPad app for Chirp It, a speech learning game for children, that would allow them to play the games on screen (Figure 2).



Figure 2. A child and his mother play with the co-design activities during the co-design workshop
(Author photos of workshops, 2018)

Clumsy Joey

Clumsy Joey is a hidden objects game consisted in creating a forest scenario and a main character that was going to guide the children through a story to ask the children for help in finding his misplaced objects. The aim of this game is to keep children engaged and entertained in the game. The co-design toolkit is created as a forest with 16 different items hidden in it. With the help of a fishing pole and magnets, participants were to role a dice that told them which item to find and they have one minute to find as many objects as possible (Figure 3). From this activity, the designers found that participants agree with making the learning process with children more interactive and fun. The findings revealed that parents like the hidden objects game and think it is appropriate and educating for children to play. In response to these findings, the students designed a prototype by translating this game into a digital app called Clumsy Joey, where the children will be able to play the game on screen (Figure 4).



Figure 3. A child playing with the Clumsy Joey activity (Author photos of workshops, 2018)



Figure 4. Prototype design for the Clumsy Joey iPad app game
(Screenshots from student team class report 2018)

Storyland

In order to make the activity interesting and engaging with the participants, the designers made the activity based on teaching foreign languages besides English – Indonesian, Chinese and Danish. The aim of this activity is to get a sense of how the game works with interruption and frustration with words that needs to be repeated. There were three story themes to choose from with one foreign language each for participant to play with (Figure 5). The designers uncovered that participants responded well as the story progressed. More importantly, participants show excitement when they see movements happening on the storyboard after they successfully repeated the word. This showed that interaction and providing a visual reward is very important. Based on these findings, the designers developed this game further into an iPad app prototype (Figure 6).

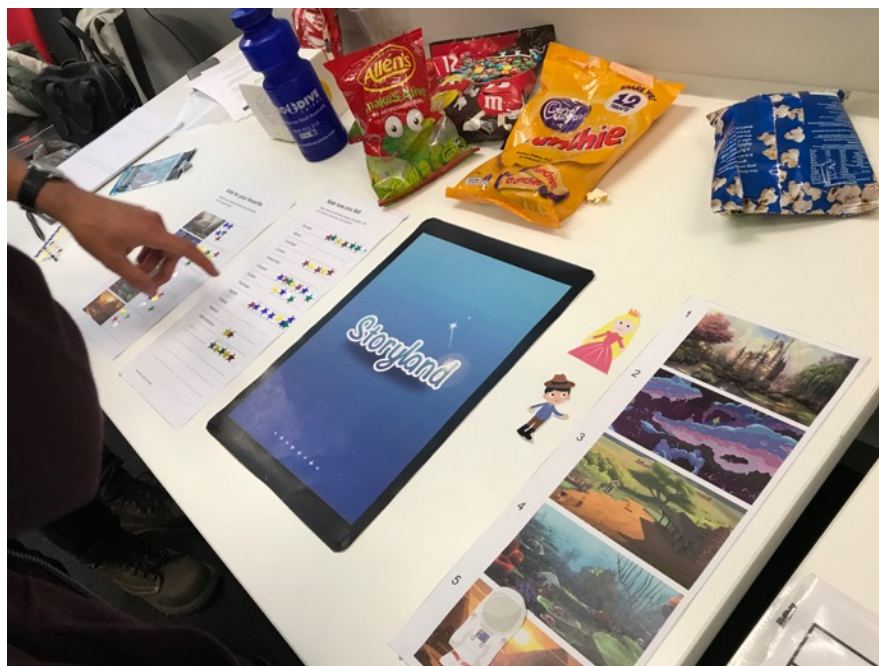


Figure 5. Storyland co-design toolkit game (Author photos of workshops, 2018)



Figure 6. Prototype design for the Storyland iPad app game
(Screenshots from student team class report 2018)

The Adventure of Maggie The Monkey

The initial idea for The Adventure of Maggie The Monkey was ChatterBox, a co-design toolkit as a major trigger for deaf children to learn how to speak and express (Figure 7). However, after the second workshop, the designers found out that the speech therapists who were participating in the co-design activity advised that the ChatterBox is more suitable for children with autism disorder rather than to help deaf children's speech learning. Hence, after long consideration and discussion, the designers came up with a new idea, The Adventure of Maggie The Monkey. Due to time limitation, they were able to develop a video prototype of how the game looks like on screen by using stop motion technique. During the final showcase, the stop motion prototype received a very good response from the lecturers and design peers as it is very entertaining and the rhyming words and songs used in the video was very catchy.

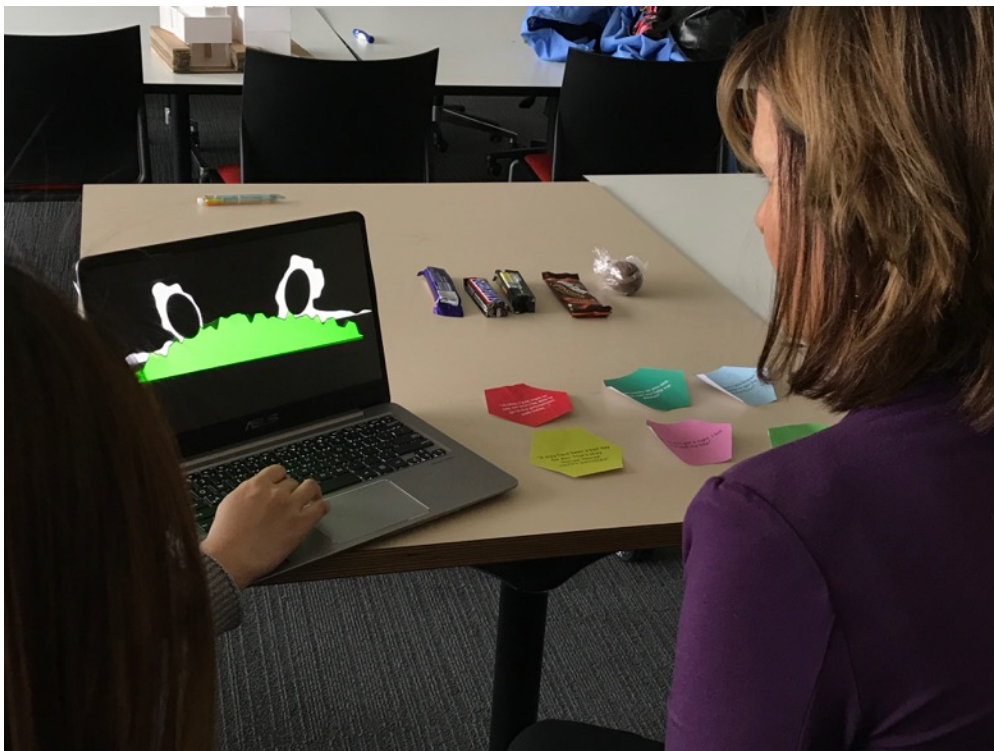


Figure 7. A speech therapist playing with Chatterbox during the co-design workshop
(Author photos of workshops, 2018)

Participant reflections

Design student perspectives

Students learned how to develop and use co-design tools throughout this unit. They received ongoing feedback on the development of their co-design tools which gave them the confidence

to feel excited about presenting their work to others. Interestingly, many students discovered that the most 'fun' activities didn't necessarily generate the most useful data. Instead, the activities that created opportunities for talking and asking open ended questions were more valuable for gathering deep insights from participants. Significantly, students found that less defined activities, or activities that allowed participants to come up with their own ideas, rather than simply rate a selection of pre-existing ideas, were the most useful.

End-user perspectives

After observing and interacting with end-users we found that the three key insights of design elements to be included in the speech learning technology are (1) sound and emotions; (2) colours for similar or rhyming words (3) phonetics. Additionally, learning by narrative appeared to be a promising idea. The use of story line and narrative in the speech learning app is something that engages children and encourages them to stay playing the game. Interestingly, one participant had a daughter who learned sign language from six to nine months old. Sign language reduced her daughter's frustration in communicating what she wanted (e.g. she would make signs when it was her snack time). On the other side, her son didn't learn sign language at all, he never attempted to do any sign at all, so it took longer for him to be able to communicate with his parents. She wished her son had learned sign language, he was always like this angry little boy because no one understood him. Learning by narrative is a fantastic idea. The use of storyline and narrative in the speech learning app is something that would distract children and engaged them to stay playing the learning game.

Design educator perspectives

The design educators approached the unit with both curiosity and a degree of concern around how deeply the students would engage with the co-design process. What we discovered was that the students were more than competent in taking the lead; from setup, to running the activities, to engaging with the participants, the students excelled at creating an energetic, engaging learning environment that exemplified the fun, democratic nature of co-design. Upon reflection, better organization of the room in which the workshops were held, and a more systematic way of allocating participants to activities, could help streamline the activity and improve student and participant experience the next time around.

Conclusion

This paper reports a case study questioning what design elements are appropriate for a speech therapy iPad application for parents of young children. Speech therapists and carers of young children were invited to co-design an iPad application with Master of Design students from an Australian University. Two workshops trialled a variety of co-design activities, over a 12-week period. This paper demonstrates that when co-designing an educational iPad speech application

for young children with hearing impairment the following requirements are preferred: (i) design for play rather than learning, (ii) gradual exposure to the application not to block interest, (iii) use a variety of imagery (dogs as the preferred animal), (iv) use popular culture cartoons and images, (v) develop lip reading as well as sign language games, (vi) allow space for getting it wrong while playing, (vii) design for privacy and personalized settings, (viii) send the young child's learning progress to the parents and speech therapists, (ix) design aged appropriate levels, and (x) focus on parents as role models for speech learning. We conclude co-design is useful for uncovering appropriate design elements when the activities are playful, colourful, and hands-on.

Acknowledgements

We would like to thank Belinda Barnet, and the speech pathologists for investing their time and industry knowledge in our co-design master class. We would also like to acknowledge the parents and all the student teams and staff for their co-designed ideas presented in this paper.

Declaration of interest statement

There is no potential conflict of interest in the research presented in this paper.

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Rethinking the Quality of an Educational Philosophy Approach and the Methods Employed in Black Mountain College Regarding the Matter of the Hikikomori Phenomenon in Adulthood

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ABSTRACT ONLY *This paper will examine the importance of an art-centred liberal arts education method provided by the experimental college, Black Mountain College in North Carolina, to address the matter of the Hikikomori phenomenon. The College serves as a part of the process in its students' lives, and for their personal growth and understanding in the form of intellectual pursuits.¹⁴ 'Hikikomori', which is originally a Japanese term, identifies a person who is self-isolated and has remained in their room for more than six months¹⁵. It can in some cases extend to more than two decades. This paper mainly focuses on this phenomenon among adults. In adults, the condition can be caused by low self-esteem and low self-confidence, resulting from societal pressure, and experiences of anxiety and depression. To confront the phenomena, to instil a sense of responsibility and a competent of one's original skills and abilities are consequential.¹⁶ The paper uses the College as an example for orienting the philosophy and methods, which focus on encountering each student's unique identity¹⁷. Through a review of Hikikomori contexts, this research concludes that the quality of an art-centered higher education can serve as a means for illuminating the Hikikomori phenomenon in a way that can return self-esteem and self-confidence to adults, and help them to become autonomously engaged in society.*

Keywords: 1* Hikikomori, self-isolation, art-centred education, higher education, education philosophy, self-esteem, self-confidence, anxiety and depression

¹⁴ Harris, M. E. (1987). The Arts at Black Mountain College. The MIT Press, Massachusetts Institute of Technology: Cambridge Massachusetts.

¹⁵ Tamaki S., translated by Angles J., (2013). Hikikomori. The University of Minnesota Press.

¹⁶ Tamaki Saito, translated by Angles Jeffrey, (2013). Hikikomori. The University of Minnesota Press.

¹⁷ Harris, Mary Emma. (1987). The Arts at Black Mountain College. The MIT Press, Massachusetts Institute of Technology. Cambridge Massachusetts.

Designing for playfulness through compassion: design for advanced dementia

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ABSTRACT The LAUGH project is a recently completed international three-year UK Arts & Humanities Research Council (AHRC) funded design research project. Outcomes from the research include a collection of playful objects designed to support the wellbeing of people living with advanced dementia that aim to provide comfort, pleasure and fun. These artefacts - a series of seven prototypes of playful objects, have recently been exhibited in London at the Royal Society of Arts, the Senedd in Cardiff and in Sydney, Australia. This visual essay provides an explanation of the research underpinning the designs and the Compassionate Design methodology that has informed the work.

Those in society who have the greatest need for excellent design are often the most vulnerable and may find it difficult or impossible to articulate what they want due to physical, sensory or memory impairment as a result of accident or disease. These people need innovative design solutions that are highly appropriate, customizable and sustainable. Finding ways to understand the challenges they face moment-by-moment and day-by-day is vital. Including them, and those who care for them, in a co-design process can provide rich insights into design requirements and result in better design solutions. LAUGH has involved key experts in dementia, including those living with the disease and their carers, at every stage in the research process.

Each of the LAUGH playful objects has been designed for a specific person living with advanced dementia. Most of them contain embedded electronics, are interactive, stimulate the senses and are highly personalized. The design narratives behind three of the playful objects will be explained in relation to the three key themes of Compassionate Design, which stress the importance of personalization, sensory stimulation and maintaining connections between people and the world.

Keywords: Dementia, design, qualitative research methods, compassion

Introduction

Over the last three years the LAUGH research team has been investigating how to design playful objects to help in the care of people living with advanced dementia (www.laughproject.info). Due to increasing numbers of those in the later stages of the disease, there is a need to find new ways to help people live *well*, and experience pleasure and fun until the end of life (Ógáin and Mountain 2015; Brooker 2007).

The LAUGH project has involved a collaboration between Cardiff Metropolitan University, University of Technology Sydney and Coventry University and a care provider: Pobl Gwalia Care and Support. It has included over 170 research participants representing more than 70 organizations.

Methodology

A qualitative and interpretivist research methodology was used to ensure the research was appropriate and informed by those who are 'dementia experts by personal experience' and those that care for them. Participatory and co-design methods, using creative and audio visual methods to gather data, have proved useful in previous research in this field, to reveal deep and complex issues (Hendriks et al. 2014). These approaches influenced the LAUGH research design process. The key methodological steps in the project involved knowledge gathering (step 1), analysis and reflection on the knowledge acquired (step 2) to inform an iterative process of design and prototype development (step 3). Evaluation was via a series of Live Labs (Brankaert et al. 2015), initially with health and care professionals to ensure safety and appropriateness of the objects and then with people living with dementia in two Pobl Gwalia Care and Support care homes in South Wales (step 4). The evaluation process is currently on-going and a larger 2-year study will include quantitative biomedical testing of the playful objects in collaboration with the NHS.

Compassionate Design principles guided the LAUGH design process (Treadaway et al. 2018) (Figure 1). These build on Positive Design (Desmet & Pohlmeier 2013) and are informed by findings from a series of previous CARIAD design for dementia research projects. This approach advocates a person centered and relational ethos in which loving kindness for the person living with advanced dementia is placed at the heart of the design process (Kitwood 1997; Brooker 2007). The three core themes of personalization, sensory stimulation and connecting with others are key to designing for people living with advanced dementia, who frequently become withdrawn and detached from the world as a result of the progression of the disease.

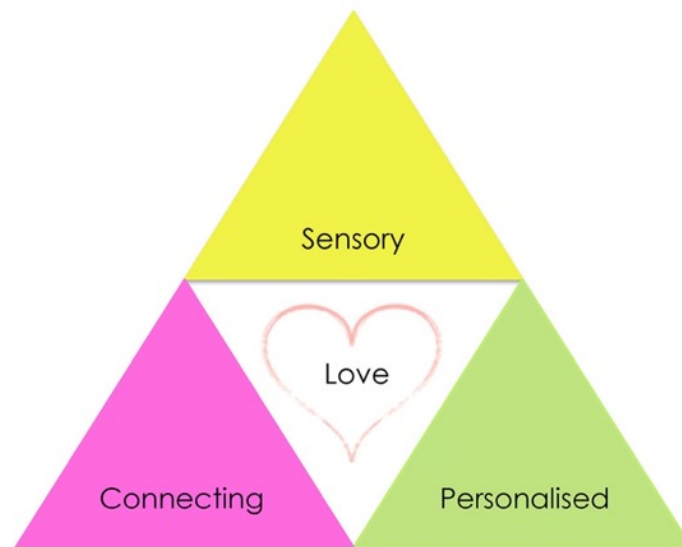


Figure 1: Compassionate Design

During the initial three LAUGH workshops, participants were encouraged to experience a number of playful and creative activities and use this to reflect on how people living with advanced dementia might experience similar activities. Participants (n=25) comprised dementia experts including carers, health and care professionals and charity representatives (Figure 2).



Figure 2: LAUGH participatory workshop: bread making to investigate hand-use

The workshops interrogated three themes in relation to advanced dementia: 1) playfulness and hand use; 2) positive emotions and emotional memory; and 3) craft activities and procedural memory. Guided by Compassionate Design principles, the design team worked directly with seven people living with advanced dementia with the assistance of family members and care professionals, to develop individual 'portraits' (personal histories and preferences) that were also used to inform design development. An analysis of the video recorded data and paper outputs from workshops 1-3 identified broad themes that were used along with the individual 'portraits' to inform subsequent co-design development workshops (n=2) (Treadaway et al. 2016).



Figure 3: (left) LAUGH Participatory workshops to develop broad themes: e.g. 'Nurturing' (right)

LAUGH Designs

The following sections explain the LAUGH design development process (step 3) of three of the playful objects.

Giggle Balls



Figure 3: Giggle Ball

Findings from the participatory workshops indicated that playful activities that induce laughter are highly beneficial to enhance wellbeing. Children's laughter, in particular, was considered likely to be infectious and engaging. In response to this, a set of six Giggle Balls were developed for a woman who had enjoyed being a bowling club member for many years (Figure 3). The balls are made of felt and contain a small tilt sensor, speakers and microcontroller containing sound files of children's laughter (Figure 4). When turned over in the hand the balls 'giggle'. Sadly, the participant passed away prior to the evaluation. However, the balls have proved particularly popular with care staff who have found them useful for changing the mood in stressful interactions with residents during the working day. One carer commented: *'If someone's sad you can cheer them up with a giggle ball.'*

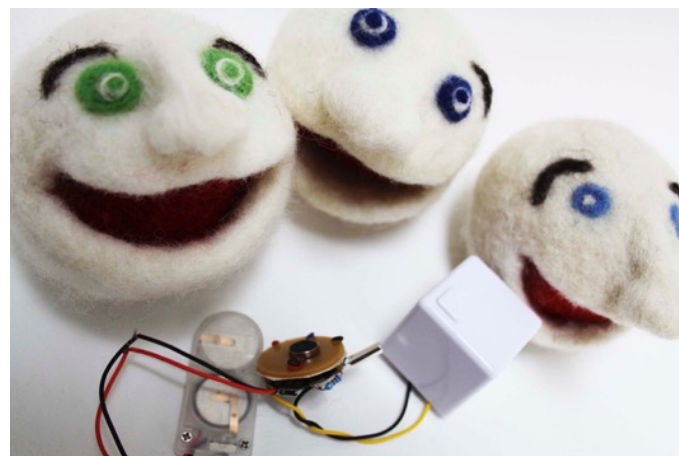


Figure 4: LAUGH Giggle Balls contain electronics that play sound files of children's laughter when moved

Steering Wheel



Figure 5: LAUGH Steering wheel

Data from the knowledge gathering phase of the LAUGH research identified two significant issues that led to the development of the LAUGH steering wheel. Firstly, people living with dementia find no longer being able to drive very depressing. This was highlighted in interviews with men living with early stage dementia who were part of an Alzheimer's Service User's Review Panel. Secondly, memories of emotional experience are retained later into the disease along with procedural memories. Rekindling the pleasurable act of driving was, therefore, used as inspiration for a design for a male resident with advanced dementia who had been a roadside recovery driver and motor mechanic. The steering wheel (Figure 5) provides haptic vibration to simulate the car engine running, has functioning indicators with lights and a 'tune-in' old fashioned radio. An embedded microcontroller enables a playlist of the person's favourite songs to be played. The Live Lab evaluation prompted a playful 30-minute activity in which the resident 'drove' into the lounge in his wheelchair and enacted an imaginary journey to the seaside to buy ice-cream with two carers at his side. The care home manager commented:

'We had a very personal journey, on a trip, and he was driving us to Porthcawl. It was absolutely the most interaction I have ever seen from him. It was absolutely amazing... it was!'



Figure 6: Health professional testing the prototype steering wheel

Hug



Figure 7: LAUGH Hug - a soft wearable object

Finding ways to comfort and bring pleasure to people who are increasingly withdrawn and unable to communicate is challenging. Hug was a playful object made for a woman with advanced dementia who was in bed for most of the day, had frequent falls, was no longer able to communicate verbally and had poor appetite and general health. Her carers suggested to the design team that the only thing she really needed was a hug. A soft cushion like wearable was designed that, when held, was reminiscent of nursing a small child. The body contains electronics that produce the sensation of a simulated beating heart and microcontroller with speakers, programmed to play her favourite music - a selection of soothing Vera Lynn songs. Hug is made from a soft washable fleece textile and is stuffed with a polyester filling.

The resident's response to hug was immediately observed to be positive and she cried when carers attempted to take it from her. Hug was left with her and the research team returned after a week, one-month and then three-month intervals to observe and evaluate. After three months with Hug, the benefits to her wellbeing were clearly evident. She was out of bed for most of the day, talking, eating better, her general health had improved, her hands were no longer stiff and contorted and significantly, she had no falls after being given Hug. According to reports by care staff and a close relative, improvements to her wellbeing could be attributed to Hug as no other significant changes to her care had taken place during the three-month period. One of the carers commented:

'She's come alive so much, whereas before she was sitting in her chair all day, not interacting with anyone, just laying there and then going to bed for most of the day. She's like a different lady now.... it's like a miracle in a way.'



Figure 8: Live Lab evaluation of person living with advanced dementia with LAUGH Hug

A larger study is planned that will evaluate the impact of Hug on wellbeing, with a group of people living with dementia and Post Stroke Cognitive Impairment. The study will involve batch prototyping and triangulated qualitative and quantitative evaluation in collaboration with the NHS.

Conclusion

LAUGH researchers have used Compassionate Design methodology in order to focus design thinking on three key areas essential when designing for people with severely impaired mental capacity: personalization, sensory stimulation and connecting to others. As well as the three objects described in this paper: Giggle Balls, Steering Wheel and Hug, four more bespoke playful objects were designed for people living with advanced dementia. These are currently being evaluated for their benefits to health and wellbeing; early results from Live Lab evaluations indicate that they have provided pleasure, comfort and stimulation to the people living with advanced dementia that they were designed for. In addition, feedback from family members and carers reveals that they also help people to reconnect, stimulating conversation and providing non-verbal channels of communication and interaction.

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Global Health Challenge: case study of a co-designed interdisciplinary initiative with local organizations in support of internationalization of curricula

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ABSTRACT *The educational practices of design and health care are changing because of the extremely complex problems being faced within contemporary society, moving beyond individually practiced subjects towards more collaborative, interdisciplinary team-based activities. To this end, education is exchanging knowledge, skills and experiences in more ambitious ways in an effort to mobilize knowledge and connect diverse subject expertise in an agile manner. It is doing so as a means of unleashing an individual and collective capacity for creativity, enterprise and innovation, in commercial and social forms. It is doing so in order to nurture an entrepreneurial mindset while offering unique real-world learning experiences and genuine exploration of alternate futures. The authors build on creative methods and the concept of co-design to develop a framework that provides a platform from which the value of new, community based interdisciplinary teams working on global health challenges can be critically discussed. Furthermore, this case contributes to the increasing awareness of design as an alternative strategy for enabling entrepreneurship while also facilitating, the potential for social and cultural transformation in design and health care, and education more broadly. It does so by indicating pathways and further application of creativity, design research and medical knowledge in the everyday world of everyday people. It closes with critical reflections and phase one insights into how universities can deliver creative learning opportunities that contribute to city life and its healthcare while concurrently addressing the internationalization of curricula for sustainable solutions to global health challenges.*

Keywords: entrepreneurial; collaborative; interdisciplinary; social justice; health and social care; design.

Introduction

Never before has the world been so interconnected. New technology has allowed unprecedented developments in the fields of design, education and health with rapid exchange of information and ideas. Concurrently, inequalities between the rich and poor are increasing with many people missing out on these advances. For example, it is a stark fact of the 21st Century that two million children under the age of five die every year of pneumonia and diarrhoea, many cases of which could easily have been prevented; 780 million people are without improved drinking water sources; and 2.5 billion people lack improved sanitation facilities. The majority of these people live in the poorest households and within rural communities. However, many of these issues are truly Global. Poverty exists in resource rich as well as resource poor countries – though it may manifest in different forms. ‘Global Health’ is therefore something that should concern everyone.

Global Health can be defined in different ways. Perhaps one of the most useful is the definition from Koplan et al (2009): ‘an area for study, research, and practice that places a priority on improving health and achieving equity in health for all people worldwide. Global health emphasises transnational health issues, determinants, and solutions... and is a synthesis of population-based prevention with individual-level clinical care.’ This clearly looks beyond the health outcomes themselves to the causes and indeed the ‘causes of the causes’.

‘Think Globally, Act Locally’ is an aphorism attributed to a number of different sources. However, it encapsulates a sentiment that it is often very challenging to make a difference to problems at a global level but much more possible to do something locally on a small scale – in this case in Dundee. Many of the major Global Health issues are visible locally in the microcosm of Dundee in Scotland. However, underpinning them all are social inequalities.

Life expectancy still differs across the city. In a 2017 report the life expectancy at birth was 76 for males in the least deprived areas of Dundee but only 68.8 for the most deprived. The corresponding figures for females were 80.3 and 76.3 (National Records of Scotland 2017). The causes are multifactorial but many, if not most, relate back to the social inequalities which persist in the city. Some of these have been highlighted in reports, for example ‘Gathering Experiences of Poverty in Dundee’ (2015) and include financial problems, in-work poverty, unemployment, poor standard of accommodation, education, mental health. Substance misuse and HIV / AIDS remain major challenges. Homelessness is also a major issue (Dundee Drop in Survey 2015).

However, there is a genuine sense of collaboration and determination to find innovative solutions that involves the City Council, business, the universities, schools as well as many charities (Dundee Fighting for Fairness 2018).

The challenge of Global Health, in part and as perceived by this work, is not poor investment or inadequate knowledge, low level innovation or an insufficient amount of passionate people. The challenge is to move co-design and holistic thinking into central strategic positions for healthcare

to create deeper, sustained interdisciplinarity and, to achieve an alternative model of practice through knowledge exchange.

To explore this problem, we use creativity and designerly thinking as a theoretical framework for mobilizing knowledge exchange across a local community and nurturing greater participation from people with diverse backgrounds. With attention to the academic context, specifically higher education institution (HEI) teaching and learning, we ask: how do people from communities across a City, form interdisciplinary teams and where, if at all, is there potential for sustained social and cultural change?

To examine this, the paper introduces Global Health Challenge as an approach to designerly thinking, specifically the method of co-design, to help facilitate social and cultural change across a community.

Creativity and CoDesign for Fostering Interdisciplinary Learning

Creativity is seen as playing a central role in helping address the challenges emerging from rapid change, in driving innovation, supporting social and economic advancement (European University Association 2007), fostering enterprise and entrepreneurship and driving the digital economy (McWilliam and Dawson 2008).

In higher education the notion of a creative graduate tends to be somewhat narrowly focussed on creative disciplines such as art, design and music. As a quality and skill creativity is conspicuous in its absence in many of the graduate attribute frameworks developed by higher education institutions (Rampersand and Patel 2014), and even in national frameworks such as the one developed for the Scottish Higher Education sector (QAA 2011). In disciplines such as medicine, there is a perceived cultural bias against creativity as the focus is on ensuring students learn the critical facts needed to become a doctor (Green et al 2016).

Creativity within medical education suffers the same pigeon holing as elsewhere, it tends to be discussed in the context of students creating artistic works (e.g. Green et al (2016). At the heart of the Global Health Challenge (GHC) is an understanding that creativity is much more than this and that community rather than the individual are central to nurturing creativity (Csikszentmihalyi and Sawyer 2014). The GHC provides a collective safe space for students to problem solve and co-design solutions to wicked problems faced by groups in their local community. In doing so it provides an opportunity for human-centred activity through interdisciplinary learning and change based on the intersection and partnership of healthcare and design (Nöel and Frascara 2016). It has parallels with the new curriculum at the Dell Medical School in Texas which seeks to train future health leaders who can apply design thinking and work creatively to solve systemic problems (Nagy 2015) through a collaboration with the College of Fine Arts.

Elizabeth Sanders and Pieter Jan Stappers (2008, 6) describe 'co-design' as 'collective creativity as it is applied across the whole span of the design process'; it is a specific case of 'co-creation', that broadly describes 'any act of collective creativity'. This view empowers people during the process

(ibid), engenders compromise during the process, and promotes shared ownership of outcome (Sanders 2010).

Studies also show that engaging people in co-design processes and co-production techniques helps promote creativity, and can lead to social benefits, such as stimulating positive behaviour changes and encouraging self-help attitudes (Boyle and Harris 2009).

Case Study: Dundee Global Health Challenge

Two projects are now used to exemplify global health challenges and how the interdisciplinary approach to GHC increases design as an alternative strategy for enabling entrepreneurship (in terms of social innovation) while providing a basis for critically reflecting on the impact of interdisciplinary team working, and collaborative partnership with local community groups.

Example 1: OpenEars

One in six people experience some form of hearing loss during their life time. *Open Ears* team found that those who are deaf or hard of hearing are commonly mistreated in multiple ways on a daily basis. In particular they found healthcare settings to be acutely challenging. For example, people going to the audiology department can miss their appointment because they do not hear their name being called out, as there is no screen displaying whose turn it is to be seen. This basic oversight inspired the team to further their research and development, speaking directly to members of the community to begin understanding their reality better. A key insight was very low awareness of the issues of the deaf and hard of hearing. As a team, they learned there are small changes everyone can make to help make a difference. These changes begin with empathy. The *Open Ears* team goal was to raise awareness of day-to-day issues that people who are deaf or hard of hearing face, and to empower the public to communicate better by providing helpful tips and tools. The team also sought to empower the deaf community to speak up and receive equal treatment in everyday society.

In response the team created a product to help improve awareness. It comes with ear defenders, ear plugs, a mask and different cards which simulate different scenarios. Their final idea is captured in a short [8-minute film](#), with a short Q&A session with some members of the team to help others with their future journey (Global Health Challenge, University of Dundee 2016). The values underpinning the designed experience are fun, interactive, engaging, sustainable, and educational. It includes cards with tips to help and also an instruction card which explains how the toolbox works. In this way, the intention is to encourage society, in a relatively immediate manner, how to become mindful of the issues and subsequently make changes to people's behaviour. There is no need for training and, no facilitator required which means it can be used anywhere by anyone. It is not too big in size and therefore fits neatly on a shelf in a small room.

Following this initiative, the team voluntarily developed the concept and its physical expression by entering the national competition Converge Challenge, and in doing so were successful in becoming finalists in the social innovation category.

Example 2: Dundee University Against Poverty Society

Exploring the challenges of living in fuel and food poverty, this team discovered they were living in the fuel poverty capital of Britain. They learned that one in four children in Dundee lived in poverty and the Dundee foodbank fed over 9,000 people in one year alone. Working with Faith in Community, a charity working in the poorest communities in Scotland to tackle deprivation and create a more inclusive environment, the team moved beyond statistics and explored the human stories underlying them. Jack was one of these. He had been his wife's main carer and he had been given a house and a car to support her. Just weeks after she passed away his benefits stopped, and he was evicted. Introductions to a wide range of local agencies along with visits to a range of charity-run community centres and drop-in services across Dundee that provided hot meals and food parcels to those in crisis situations revealed similar stories and further insights.

The team identified a pattern of problems across these charities such as mental and physical health, stigma, engagement, food and fuel poverty and education. The lack of education around food was a massive issue, with many people not having the skills or equipment to cook cheap and nutritious meals for themselves. They considered developing a set of cookery classes, cookery videos and cards. Further research indicated that cookery classes were already running and that online videos would not be accessible as their target population had no internet access. Other groups were also already producing cookery cards.

Realising their ideas were doing little to enhance existing services, the team identified the real need which was to improve networking between the existing local organizations. There were also challenges around volunteering and concerns of sustainability due to an over reliance on older volunteers.

Here was an opportunity to get a big student population engaged with the local community by establishing a new society, Dundee University Against Poverty. Local agencies were very receptive to this idea and further dialogue revealed that whilst some did not face problems with volunteers, they had other issues they felt students could work in partnership with them to address. The Society has formally launched and is actively networking across Dundee charities, promoting volunteering opportunities, and at the end of the 2018 academic year collected hundreds of items from students to create starter packs for people who were previously homeless and moving into accommodation. They are exploring plans to develop a pay forward scheme for hot drinks and food to support those struggling, through the mobile YoYo Wallet app that could in turn be distributed through their links with local food banks.

Critical Reflection and Insights: phase 1

How can universities deliver creative learning opportunities that contribute to city life and its healthcare while concurrently addressing the internationalization of curricula for sustainable solutions to global health challenges?

On one level, GHC explores how best creativity can be used to nurture greater engagement with people in a variety of creative activities to foster change. It is an example of how co-design is used as a means of achieving collective creativity, making an impact on generating social and cultural value, including societal engagement and positive change in attitudes and behaviours. The city therefore is providing an ideal crucible for collaborative working between students, staff and local organizations to work together with local communities to develop practical local solutions to real-world Global Health problems. At the same time, it is helping to educate students, who will be the leaders of tomorrow, about the social issues around them.

We observe the social value that is generated through ideation, creation and implementation of new ideas about how people organise interpersonal activities and social interactions to meet common goals, and how the GHC process is helping social enterprises meet their business needs in a way that achieves value for money in a holistic sense as the human centred relationships are generating benefits to society (e.g. increase number of volunteers) and the economy (innovative new product and service design, and societies).

Summary and Closing Remark

GHC fosters creative people, communities and organizations in an inclusive manner through a combination of imaginative interventions, shared social learning spaces and online learning resources. By design and through carefully curated facilitation, it embeds an entrepreneurial character in how to develop genuine solutions when tackling the thorny problem of health equality under a range of themes. Each person is gifted with learning and practicing five skills for enterprise: creative problem solving; deep listening; immersive empathy; networking and visualization. Everyone at each stage is encouraged to see the world differently, to be concerned with social justice, to lead with questions and uncover deep insights – receiving input and partnership support from local organizations, industry speakers and recognized mentors from business, design, healthcare and academia to inspire and inform their work on innovation.

The case presented in this paper derives from the first phase of delivery and is an introduction to the problem, methods and process. The next stage is to conduct interviews with the partner organizations and, through a survey with students, ascertain where, how and what, (if any), are the sustained changes to social and cultural change being nurtured by GHC.

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Animated instructions for medicines: Who can assess the quality and effects?

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ABSTRACT *Information for patients about medicines is a global problem. Texts are incomprehensible, hard to read, difficult to apply, and very hard to relate to other information. The Regulatory Authorities (Food & Drug Administration, European Medicines Agency) are aware of this and keep suggesting improvements. Despite many efforts patients do not receive information about medicines in a format that they can use. The pharmaceutical industry, pharmacists, hospitals, and insurance companies are developing additional information sources on websites, on smart phones, and as ‘patient education materials’. These documents are still tightly regulated, but provide alternative information sources for patients. The quality and benefits of all visual information sources need to be evaluated. During the development of animations about treatments and medicines, it became clear that there are at least six different groups of people who can assess the information about medicines. These are:*

- a. the writers/designers: applying linguistic and visual criteria*
- b. the client: applying commercial and strategic criteria*
- c. the regulatory authorities: applying legal criteria*
- d. professional disciplines (writers/designers/doctors/pharmacists/nurses): applying disciplinary criteria*
- e. patients: applying health criteria (finding, understanding, applying information to maintain or improve health)*
- f. society: applying civil criteria (sustainability, cost/benefits, public concern)*

In order to establish if a simple animation is acceptable, it was necessary to apply the often mutually exclusive criteria of all six groups. A focus on the needs of patients is an essential starting point, but the other perspectives must be considered too. Balancing these remains a major issue and makes compromises unavoidable. Toulmin’s argument layout offers a useful approach to discuss the relevance of the six perspectives for the design of information for patients.

Keywords: information for patients, information about medicines, animation, visual, quality assessment, Toulmin’s argument layout.

Introduction: well designed information for patients?

Providing patients with information about their medicines is an essential part of a therapy. Without information it is very difficult to find out when and how to take medicines, what their purpose is, and which potential risks they might cause. Professional healthcare providers (doctors, pharmacists, nurses), industry, carers (family), and different media (television, internet, newspapers) contribute information at different points in a therapeutical process. For individual patients, this information is not given in a coordinated manner, and it is not provided in formats that are easily accessible, understandable, and applicable in specific situations.

Medicines information is strictly regulated and aims for neutral and objective instructions. At the moment, most of the regulated information is on paper, although the same information can be downloaded as pdf-files or can be seen as a webpage. The visual qualities of the design of this information is often of a poor standard and leads to confusion, errors, time-wasting, and frustration (van der Waarde 2017). This issue is recognized in Europe by both the European Commission (2017) and the European Medicines Agency (2017) who have set out strategies to remedy some of these problems.

The pharmaceutical industry, pharmacists, doctors, patient organisations, and hospitals all develop alternative formats to satisfy the needs and expectations of patients. All are based on the regulated information, and all add their own perspectives and priorities. Figures 1, 2, and 3 show examples of stills of animations that are funded by the pharmaceutical industry, patient organisations, and hospitals.

Developing alternative forms of information

Based on the experience with patient information leaflets, in combination with research results, the approach to provide information about medicines for patients is changing. There are at least six major shifts:

- focus on a specific medicine (not a standardized 'one-size-fits-all' for all medicines)
- focus on correct use in actual context (not on an 'imagined use' in an 'imagined context')
- combine text and images (text on its own is not enough)
- combine information on paper and digital information (paper on its own is not enough)
- shift from a medical/legal genre towards a healthcare and patient-focused genre
- cooperate with patients, doctors, and other healthcare professionals (the development of information cannot be done independently).

Although there are some indications that these shifts have lead to more effective information about medicines, convincing evidence is still missing. Figures 1, 2, and 3 give examples of the questions that need to be answered. But before empirical studies can be designed to answer these questions, it is first necessary to list what kinds of evidence might be most useful.

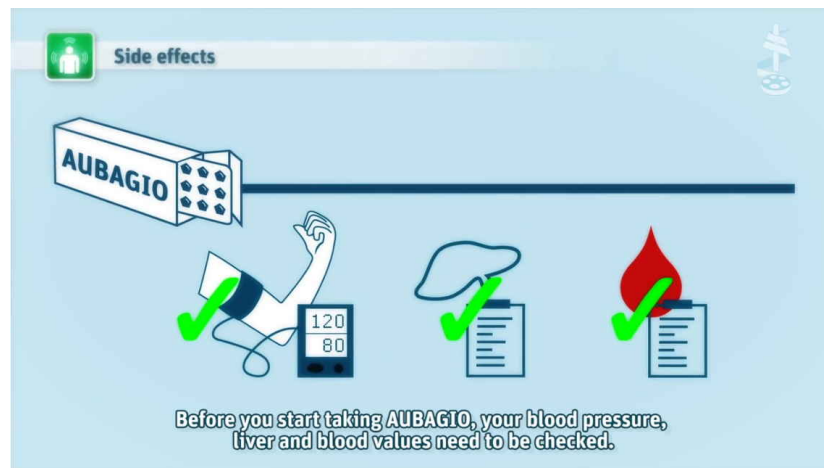


Figure 1: Which value systems can be applied to assess the quality and effects of this animated instruction?

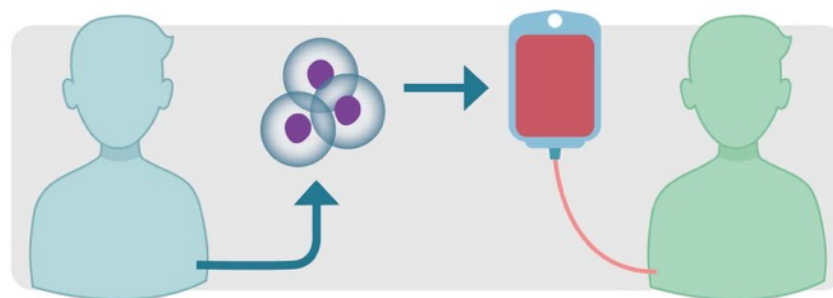


Figure 2: What kinds of knowledge tests could provide an indication if low literacy, low health literate patients understand explanations?

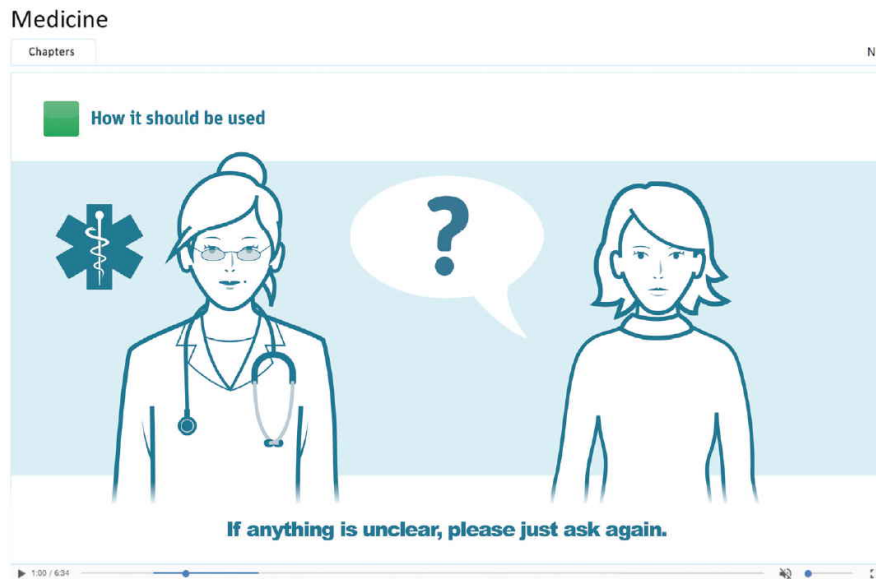


Figure 3: Who benefits from animated visuals?

Quality assessments?

During the development (writing, designing, testing) of the animations in a commercial design practice, it turned out that there are at least six groups that could provide a relevant assessment of the quality of the design of these animations.

These groups are:

- **The designers.** This group consists of writers, designers, usability-testers, and programmers. This group applies linguistic, visual, and design criteria.
- **The client.** Commercial or governmental organizations focus on financial and strategic criteria.
- **Regulatory authorities.** This group applies legal criteria, and considers standards and guidelines.
- **Professional disciplines.** Most professions (writers/ designers/ doctors/ pharmacists/ nurses) are represented by disciplinary bodies. These bodies develop and apply disciplinary criteria and professional protocols.
- **Patients.** Patients – and their carers - apply criteria related to health. They need to find information, understand information, and apply information to maintain or improve health.
- **Society.** A society applies civil criteria such as sustainability, cost/benefits, and public concerns.

One of the major challenges to develop information for patients about medicines is that these six different groups need to be considered simultaneously. The difficulty is that the criteria of each of these six groups cannot be easily related to each other. Some of them are even in direct conflict. For example, information might be designed well, for an acceptable price, very usable according to professional standards, and societally acceptable, but if it is not adhering to the legislation, it still will not be accepted. At the moment, the assessment of package leaflets – the ‘stuffers’ as they are found in every medicine pack in Europe – is heavily inclined towards the criteria of the regulatory authorities.

Discussion: a theoretical approach?

How can these different perspectives of these six groups be resolved into a consensus that is acceptable for all? What kinds of evidence is convincing for these groups, and would a group accept evidence that is not related to its own focus? One possible approach to relate the different arguments for different situations is to apply a standard description of an argument. Stephen Toulmin (1958) published an analysis of the different parts of an argument and their configuration. Figure 4 shows the general layout of an argument.

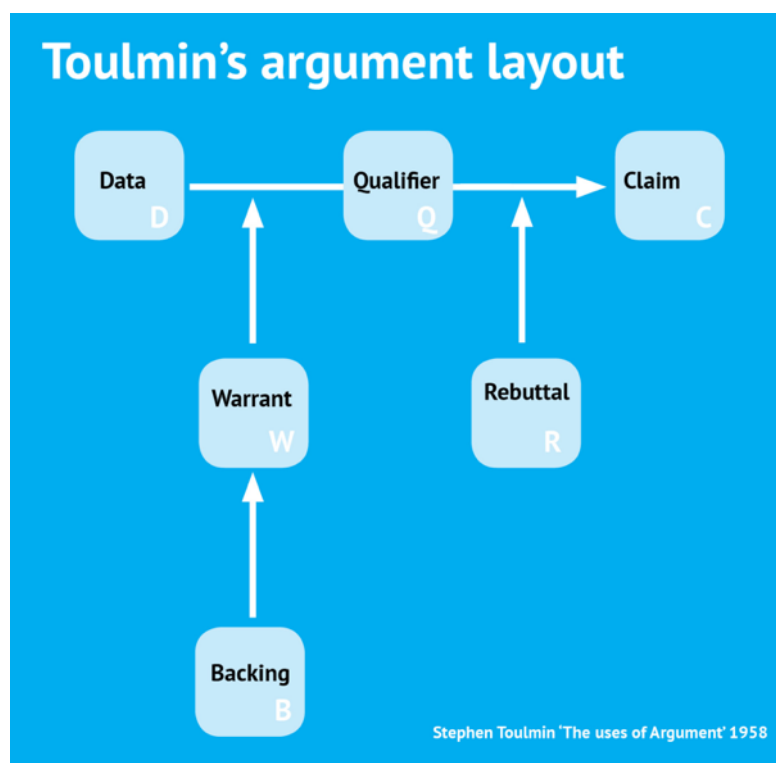


Figure 4: Toulmin's argument layout ('*The uses of Argument*', 1958) suggests the necessity to explicitly describe the warrants and backing in order to make a valid claim.

A very brief description of Toulmin's diagram is as follows. If we want to make a convincing claim (C) then we need to provide data (D) to support that claim. We also need to qualify (Q) this claim because it is unlikely to be applicable everywhere at any time. We need to justify

the relation between the data and the claim - a warrant (W) - by referring to general rules and principles. And we might need to provide reasons why these general rules are relevant by referring to an authority: the backing (B). And lastly, we need to consider the conditions of exceptions in which the claim cannot be correct. This is the rebuttal (R) or refutation. The argument layout has been discussed for over 60 years, and continues to attract academic attention (Jackson and Schneider, 2018).

It seems that the provision of information about medicines to patients can be seen as an argument. It is a series of statements to persuade a patient to take medicines correctly and effectively. Toulmin's diagram shows which parts of an argument need to be considered to support this claim. The animated instructions of figures 1, 2, and 3 are used as examples to relate the design of visual information to Toulmin's diagram.

The claim (C) that designers make is that '*well designed information enables patients to act appropriately*'. In order to make this claim, designers need to provide evidence and data (D) and qualify this claim. The qualifications (Q) for the animations are that they are specifically made for low-literate and poor health-literate patients in the Netherlands. Some empirical evidence is provided by the results of usability tests and comprehension tests. Results of academic studies further support this claim by providing evidence that current patient package inserts are problematic, patients struggle with medical terminology, and adherence to medical regimens is poor. All together, this provides facts and evidence that the animations perform better in practice than the original regulated package leaflets. At least patients can understand the information, remember it, and find it when they need it.

The warrant (W) – or the justification that this evidence is relevant for the claim – is provided by the idea that people can understand and remember 'combined media' better than 'text only'. The animations use a combination of moving visuals, static visuals, text in captions, text in pictures, spoken words, and music. It is inferred that the general rule can be applied to information about medicines. The backing (B), the 'kind of authority' this approach relies on, is both practice based ('it seems effective in the real world'), and its findings in fields like cognitive psychology and applied linguistics are related to memory and understanding. The rebuttals (R), for the designer's claims, look at the exceptions and refutations. For the animations, these rebuttals relate to the visually impaired, the hearing impaired, and digitally challenged patients who have difficulties watching the animation.

Toulmin's model nicely indicates why this 'design argument', with its evidence, qualifiers, warrants, and backing, is not persuasive enough for the other five groups who can assess the qualities of the animations about medicines. For example, clients have difficulties in relating this argument to the financial and strategic criteria that are relevant to their activities. Questions like 'what are the financial consequences if patients understand and remember information about their medicines?', and 'how easy is it to modify this information if changes need to be incorporated?' are outside the design realm and are rarely dealt with by designers. Regulatory authorities struggle with these animations too because there are no guidelines or legislation that could help to assess them. Patients mainly focus on their

health, and the design arguments don't really address this. The real health benefits for patients of well understood and applicable information remains uncertain.

In general, based on Toulmin's diagram, the warrants and backing of the different groups are very hard to combine. The evidence that designers provide to support their claim needs to address the financial, legal, disciplinary, usability, and societal criteria too. It is not simply a matter of 'producing a considered argument' from a design perspective. All other perspectives, which might be internally subdivided even further, need to be addressed.

Toulmin's model, and especially the warrant and backing provides a clear theoretical description of the fundamental cause of the poor information that patients receive when they need to take medicines. At the moment, the emphasis is mainly on the regulatory and economical perspectives. Information for patients about medicines follows the legislation, and is produced for the lowest possible price. The other perspectives, such as the health perspective of patients do not receive as much attention. In order to develop information that would really enable patients to act appropriately, it seems necessary to address the arguments from the perspectives of the other groups too. This means that it is necessary to find relevant evidence in areas that until now have received insufficient attention from designers.

Conclusion

Providing patients with relevant information about their medicines is still problematic. There are at least six different groups who can provide an evaluation of the quality of this information. In practice, these six groups have very little in common, and assess information based on different criteria that are related to different value systems. A designer needs to consider design, finances, legislation, disciplinary habits, health, and societal preferences simultaneously, and try to find a balance between all of them.

Toulmin's argument layout provides a visual representation of this fundamental conflict of interests. Each design makes a claim that it is an improvement in comparison to the existing situation. The evidence to back up this claim needs to convince at least six different groups. This requires different kinds of evidence to allow for different kinds of warrants and different kinds of backing systems.

It is now possible to set up specific experiments that investigate the consequences of the animations for these six different groups. Although it is likely that some experimental results will be rejected as irrelevant by some groups, these results will add to strengthen the relevance of design in the provision of information about medicines for patients.

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WORKSHOP: Methods of cross-over research: A co-creation navigation tool for design for health

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ABSTRACT *A cross-over collaboration between the fields of health and design brings together disciplines and participants of highly diverse natures, each with their own perspectives, interests and research discourses. Interdisciplinary research groups are formed, and different research methods are combined. This is not an easy task. In the cross-over research field of design for health, the research methods of the creative industries need to be combined with those used in the healthcare field. As a result, researchers in a cross-over collaboration need to push the boundaries and go beyond their own 'comfort zone' to be open to approaches that are unfamiliar and may prioritise different sets of values, but nonetheless are valid.*

The Co-Creation Navigator - a co-creation kit based on the expertise and experience of Waag, being developed in the context of the European BigPicnic-project – takes centre stage in this workshop. The Navigator is both an online, open repository of methods and a guide, that guides users through different stages of co-creation, from preparation to execution and reflection. Target groups are professionals wishing to engage in co-creation with diverse stakeholders. The workshop will explore what specific requirements, bespoke tools, and evaluation methods are needed, by working with the (open) contents of the Navigator in the context of design for health.

Keywords: co-creation; cross-overs; health; design; research methods



The Navigator uses the metaphor of a subway map to guide you on your journey through the different stages of a co-creative process

Introduction

#WeAreNotWaiting. A group of concerned parents decided to develop an open source, Do It Yourself digital self-management tool that helped them better manage the blood sugar of their children (diagnosed with Type 1 Diabetes), as commercial systems were not providing the feedback they needed to monitor and support their children. Inspired by a vast amount of online open information on software and hardware development, they took on a role as developer and produced remote access to blood sugar information of their children. A Facebook-post brought these parents in direct contact. With *Nightscout* (Continuous Glucose Monitoring in the Cloud) they devised a tool - through reversed engineering of an existing commercial technology – that allows parents remote monitoring of their child with diabetes. By developing *Nightscout* citizens have taken matters in their own hands and started a revolutionary movement in digital social innovation in healthcare. So, be impatient! (Lee et al. 2016)

Nightscout is a shining grassroots example of citizen driven, social digital innovation. Over recent years citizens, including many patients and caregivers, became impatient and started developing personalized devices and tools that provided support to meet their needs. Access to the Internet, open source information and digital tools empower citizens, including patients, caregivers and healthcare professionals, to improve the self-management of their disease or to develop aids that support them in coping with daily hindrances of physical limitations. A growing number of grassroots solutions saw the light of day: from open source hand prosthetics, 3D printed writing

tools to support kids with physical limitations, to add-ons for wheelchairs, and everything in between.

Bottom-up digital social innovations

Bottom-up digital social innovations are on the rise, including in healthcare. Innovators, users and communities in healthcare are starting to collaborate by using digital technologies to co-create knowledge and solutions for a wide range of needs. These innovations are at a scale that was unimaginable before the rise of the Internet (Bria et al. 2014). Examples that add to this experience are *eNable*, where an owner of a 3D printer used this technology to print a hand prosthesis, based on a prototype from the early 1800s (Knochel et al. 2018). His technical information was published open source and adopted by a growing group of 3D printing engineers that provide people in need with customized 3D printed hand prosthesis. Or *OpenAPS* in which a female engineer with Type 1 Diabetes developed a DIY Open Artificial Pancreas System based on existing approved medical devices in combination with commodity hardware and open source software and it was designed primarily for safety, simplicity and interoperability with existing treatments (Lewis et al. 2016). These examples have been developed thanks to open source and low-cost open hardware, Internet of Things, crowdsourcing of knowledge and skills and access to digital fabrication tools.

An inspiring example has been the co-production and replication of a tricycle for Lorenzo, a 6-year-old who suffers from a complex neurological pathology that makes most daily actions difficult (see: figure 1). The patient organisation TogetherToGo teamed up with Milano's Fablab Opendot to engage in co- design, customization and rapid prototyping to produce a tricycle with reduced cranks, ergonomic saddle, support for the back and adjustable handlebar (see: figure 2, 3 and 4).



Figure 1: Tricycle Lorenzo

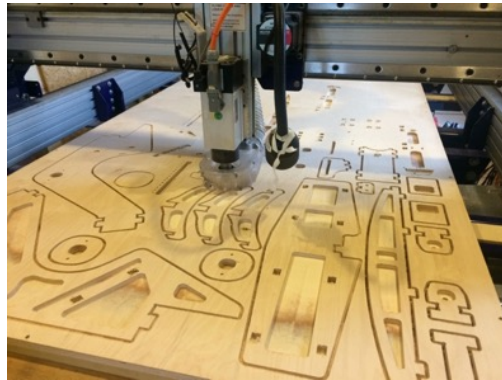


Figure 2: Using fablab to produce the tricycle



Figure 3: Detail of the tricycle



Figure 4: Lorenzo on his tricycle

The 3D model is customized for Lorenzo, but can be quickly adapted to the needs of other children with different disabilities (see: figure 5), using personal digital fabrication. In the Netherlands a replication of Lorenzo's bike has been made in the Fablab of WAAG, showing the potential of 'open' healthcare solutions (see: figure 6).



Figure5 : Tiziano and Luca taking measurements for new custom size bicycle for Viola



Figure 6: Replication of Lorenzo's tricycle

Increase accessibility healthcare solutions

Open source solutions as mentioned above, increases the accessibility of healthcare solutions. This accessibility towards healthcare fits into the framework on integrated people-centred health services, as published May in 2016 by the World Health Organization (WHO 2016). The WHO proposed a fundamental shift in the way health services are funded, managed and delivered through empowered and engaged citizens within communities. The WHO envisaged, in this framework, that all people have equal access to quality health services that are co-produced in a way that meets their life course needs and respects social preferences. The envisioned health services should be safe, effective, timely, affordable and of acceptable quality. The framework can be adapted to all countries whether high, medium or low income as well as mature or fragile health systems. Open healthcare solutions, like *Nightscout*, illustrate the WHO framework and deliver health services that meet the needs of citizens, empower and engage communities and are co-produced by the users.

With the emergence of fabrication laboratories - over 1.000 labs worldwide - and makerspaces, the possibilities to use digital fabrication techniques, such as laser cutters, Computer Numerical Controlled (CNC) milling machines and 3D printers, have become readily available to create opportunities to allow citizens and communities to develop and produce personalized solutions and innovations in healthcare and have the ability to change the production process in healthcare.

Enable citizens to co-design

The mission of the European funded project Made4You is to enable citizens to co-design and deliver personalized, people-centred health solutions, using digital fabrication (see figure 7).

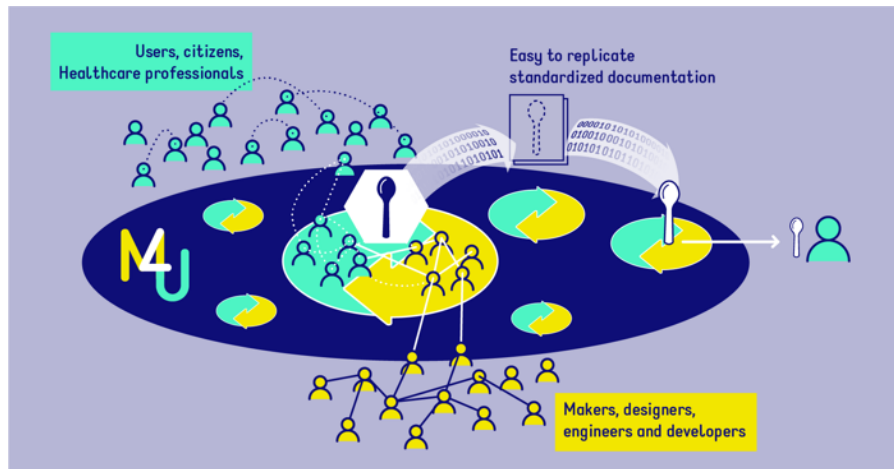


Figure 7: Made4You Vision for Personal Making of Open Healthcare solutions

To establish such an ecosystem of open healthcare solutions an open and online platform is required that:

- Connect existing communities of makers, engineers and fabricators with communities of citizens (including patients) and healthcare professionals;
- Co-design open healthcare solutions for citizens facing physical disablements, and for healthcare professionals to improve the healthcare services they provide;
- Improve access for citizens to grassroots healthcare solutions via co-design methods and open standard documentation, and provide them the tools to become active innovators;
- Establish a wide user-base open and dedicated platform to share and exchange open healthcare solutions as well as co-design experiences;
- Collect available existing solutions and make them more accessible via open standard documentation on the platform.

Made4You's ambition is to establish **the central hub Careables for citizens worldwide to find open healthcare solutions** that can be customized to adapt and self-manage physical conditions to their own needs and wishes, and understand how to make solutions real (see figure 8).



Figure 8: The Careables platform

The online platform is the linking pin to different user groups, from people with physical limitations to makers, from engineers to healthcare professionals. Made4You also includes private corporations, donors and co-funders to connect and provide financial contributions to fund specific solutions or kick start the production process. Made4You aims (1) to offer open healthcare solutions on a central space, where they easily can be found and shared and (2) that the solutions are **fully documented** in an open source way so citizens are able to replicate solutions in any local lab or makerspace. This open and inclusive approach is an alternative model to sustainable, affordable and personalized healthcare services.

Current open source healthcare solutions have their own dedicated platform for technical documentation and user experiences, such as *Nightscout* or *EchOpen*¹⁸. As the amount and complexity of open source healthcare solutions increases, the urgency for a proper classification increases as well. Like the open source 3D printed prosthetic hand of *Enable* that contains multiple components and areas to work on such as casting of the limbs, printing of socket and fingers and the assembly process.

The knowledge, improvements and insights on all of these areas need to be included on a central platform. As Made4You is an inclusive hub for a wide variety of open healthcare solutions the classification of solutions and sub-classification of components is crucial. Therefore, Made4You draws on the expertise the renowned Fab Labs and GIG-members to align **requirements for the classification**. In an iterative co-creation process with stakeholders this classification is designed, developed and tested. The underlying platform technologies are based on the existing platform technologies of Wevolver, which has been awarded for its innovation potential¹⁹.

¹⁸ <http://echopen.org/> [Accessed: July 20th, 2018]

Made4You's ambition is to **increase the existing knowledge and expertise** of communities of makers, engineers and designers, and citizens, patient groups and healthcare professionals to achieve a fundamental shift in development and delivery of open source healthcare solutions. Made4You is the first project to support this paradigm shift through the integration of an online platform and physical labs and makerspaces. The approach of Made4You and the tangible outcomes differs from projects like *OpenCare*. In *OpenCare* the main focus is to engage communities with online tools that is guided by community managers. During workshops, co-creation sessions, meetups, and other interactive gatherings new open healthcare solutions are designed with the different stakeholders in an open approach to design (figures 9-12).



Figure 9 and 10: Saddle up specially made for Anna (Opendot)



Figure 11 and 12: Designers, healthcare professionals, carers and people with a care need designed and realised new healthcare solutions at MakeHealth workshop series (WAAG)

Made4You involves stakeholders directly and locally; the Fab Labs and makerspaces within the consortium function as physical innovation hubs. The use of an open standard and documentation tool enables every Fab Lab or makerspace in the world to get involved, enabling a global impact.

The proposed workshop at Design4Health 2018 is to involve designers in the field of healthcare to critically reflect on and question the potential of co-design of 'open' healthcare solutions. Thereby creating insights and increase the knowledge on 'How to increase accessibility to healthcare solutions through an 'open' design approach, using the principles of digital fabrication to produce the solutions locally with the community?' And to thrive towards the establishment of a sustainable model for open source healthcare solutions.

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Visual and Material Slang: Improvisation and Healthcare Design

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ABSTRACT *Improvisation could be frowned upon as an action of disruption, creating an irregularity in design systems and processes. However, improvisation in design could lead to innovation and imaginative and necessary solutions. When researching modes of improvisation through the eyes of the design partners, i.e., the end-users, these innovative and bottom-up solutions highlight the shortcomings of the original design. On its own, creating a circular movement between the end-user and the designer can redefine the dialogue between the two. Furthermore, viewed from a linguistic and hermeneutic point of view, improvisation in design holds a crucial role in invigorating and refreshing the material and visual design language. This is especially true and immensely important when dealing with healthcare situations. In fact, we claim that the secondary design, resulting from bottom-up improvisation is a necessity that should be reflected and embedded in the original design of healthcare products.*

Keywords: design language, improvisation, healthcare, design theory

Improvisation in Design: What and Why?

In various disciplines, improvisation is perceived as a lack of professional integrity or knowledge. However, in healthcare design, we believe that improvisation is in fact an inherent necessity, stemming from a much-needed flexibility. Adding to this surmise the varied mental and physical attributes of patients, we believe healthcare products should be designed with an inherent ability to change and improvise according to each context in which they are used.

We can look at reality from two differing yet complimentary perspectives. A classic attitude would be to think of reality as embodied in standardized processes, based on inertia, stability and repetition. Another would view reality as a nexus of innovative, creative, unrepeatable and unexpected movement forward (Barber 2007). Instead of viewing improvisation as a disruptive element at worst, or amateurish redesign, we wish to view it as an innovative reassembly, necessary in a hospital environment to create a better dialogue between the various design partners in each design situation. Indeed, in our case, improvisation could be seen as acting “in a context of a negotiation as a coherent sequence of relational, informational and procedural actions and responses created, chosen and carried out by the parties during the social interaction” (McGinn Keros 2002, 445). As in music, in some design situations, as we shall in the case of rehabilitation, improvisation is a way of life (Lewis and Piekut 2016). However, contrary to its serving an innovative and creative artistic cause, in healthcare design improvisation is a survival way of life. Innovating in a strict economic and socially as well as professionally complex system leads to improvisational innovation as an almost necessary design tactic, echoing the famous anthropological theory of adaptation.

As we shall see, while the latter is enticing, the reality in a hospital environment favours the former view. Ingold and Hallam (2007) describe improvisation as comprised of four attributes: first, it is generative, i.e. it gives rise to forms of culture embedded in a specific context. This generative character is a key feature in healthcare design, whereas objects and services evolve through a network of design partners over time in a specific environment. Over the years, generations of healthcare professionals add and trim the progress of improvisation. Second, it is relational, in that it is affected and generated by social interaction, but not in a metaphorical way. The design situation rests on a continuous dialogue between the various design partners, through the mediation of objects or services. Third, it is temporal, in a sense that it holds a certain duration and the potential to become the new standard over time. The paradoxical nature of design is that it embedded in the past and aimed at the future, while trying to make an impact in the present. Finally, simply put, it is the way we work, both as designers as well as researchers. In sum, ‘improvisation and creativity are intrinsic to the very processes of social and cultural life’ (Ibid., 19).

In these instances of design improvisation is embedded an innate potential of agentic power. Following Gell’s (1998) seminal work, we see the act of improvisation as an agentic action emanating from individual perception and embedded in systemic restrictions. As de Certeau (1984) termed it ‘tactical manoeuvring’, the healthcare professionals read the organizational

situation in which they operate and create an innovative interpretation of their own, based on an existing product or service.

Improvisation Design and Healthcare

From a classic managerial or system-oriented approach, improvisations could seem as dangerous outbursts with the potential to jeopardize the organization's carefully built production system (Cunha and Pina e Cunha 2008). However, in healthcare situations such as hospitals as we shall see, improvisations could manifest a true and urgent need which is yet to be met by the original design of various products. Furthermore, improvisations could mean the original design is just not compatible with the end-users' needs, or has been rendered outdated by technological or social changes.

The action of improvisation could be understood in various possibilities. First, it is a creative act of innovation, stemming from an inherent trait or ability to adapt to an ever-changing reality. Through this lens, the act of improvisation includes the location and identification of a 'crack' or a shortcoming of a product of a situation. In a way, following Latour's (1996) description of looking for the cracks in the discourse, the act of improvisation highlights or points to a crack in the design, allowing for potential change and innovation. Therefore, in various areas of design, an almost inherent and systemic ability to improvise is crucial:

'Within performance design, for example, there is no ideal of being able to control and decide everything down to the smallest details before the performance. A performance is precisely characterized by the possibility for improvisation and interaction between performer and audience. In other words, a creative process in the here and now is essential' (Christrup 2010, 157).

Gerber (2007, 1069) continues to define improvisation as 'a creative act composed without prior thought', deeming it an important part of design process. Indeed, designers focused on tools designated to support improvisation, but design, as we can see, holds the potential to enable and even encourage improvisation as a creative way of adaptation. Gerber continues to highlight five key layers of design improvisation: (1) **Creative Collaboration**: as was presented along this article, in healthcare design, various layers of users create a material dialogue through interaction with objects, services and environments; (2) **Fostering Innovation**: in this case, innovation stems from necessity and the ability to adapt to a system of changes; (3) **Supporting Spontaneity**: while spontaneity could harm a classic design process, in the case of the 'second life' of the object in healthcare situations, spontaneous change could mean in some cases the success or failure of an object's use; (4) **Learning through Error**: in healthcare situations, the ability to perform a task is key and therefore failure can generate innovation and change; and (5) **Developing Presentation Skills**: while apparent in Gerber's model and in classic design process, in healthcare design where marketing is secondary to performing a function, this attribute is less relevant.

In fact, harnessing spontaneous or bottom-up improvisations especially so when dealing with healthcare design, helps negotiate and bridge between design and reality (Herman Shidende et al. 2017).

Improvisation Design as Visual and Material Language

Going back to the model of 'design situation' and highlighting our innovative approach – the essence of creativity is generated by the innovative stance of the users (first and secondary users in our case – the medical staff) and not by designers. In fact, through the understanding of 'adaptation' as a human trait, the secondary process of spontaneous design starts after the designer finished his 'rigid' design, rendering a more flexible approach through the action of the medical staff. Naturally, this occurs through a process of negotiation and interpretation via the action-based material dialogue between the medical staff and the patients and the medical organization. In other words, while necessary in nature, vis-à-vis the necessity of adaptation in healthcare design the users generate a process of innovation and creativity that could be described as a 'hermeneutic second stage' of design.

Several factors influence the essence of this 'bottom-up' improvisational approach towards healthcare design. First, it is temporal in nature, meaning that time has an immense impact on the scale and scope of the improvisational result. As time is of the essence, immediate changes stemming from the intense character of physiotherapy, improvisation happens quickly. Second, as a spontaneous and necessary action, design improvisation in our case is generated by the first and secondary design partners, both of which have no professional design training. Each, however, uses their unique knowledge to express needs and constraints. While the patients build on their own subjective and personal experiences as end-users, healthcare practitioners build on their universal and objective knowledge, targeted at a mass of potential patients.

Interestingly, we can surmise that similarly to classic design process, as well as bottom-up improvisation, this evolutionary potential stems from the strict boundaries imposed on these two venues of design. While different in nature, restricting boundaries helps creativity and dealing with stress in the studio (Ventura 2014). However, while the restrictions in classic design process are embedded in the design brief (Ventura and Ventura 2015), in our case, it is embedded in the material presence of the finished designed object. As the users cannot incorporate a classic design process targeted at mass production, reality dictates strict boundaries and possibilities in a natural and rigid fashion.

From a classic managerial or system-oriented approach, improvisations could seem to be dangerous outbursts with the potential to jeopardize the organization's carefully built production system (Cunha and Pina e Cunha 2008). However, in healthcare situations such as in hospitals as we shall see, improvisations could manifest a true and urgent need which is yet to be met by the original design of various products. Furthermore, improvisations could mean the original design is

just not compatible with the end-users' needs, or has been rendered outdated by technological or social changes.

Improvisation and the Impact of Design Partners

Due to the short length of this paper we will present two case studies, alluding to the potential of improvisations in healthcare design. In these examples, we will highlight the importance of the design partners' contribution to the design of healthcare products. The first example will be based on the actions of healthcare professionals, i.e. physiotherapists, while the second will be focused on the social aspect of improvisations – i.e. the patients. Both examples are located at the rehabilitation unit at Hadassah Hospital in Jerusalem, as a part of a lengthy design research which started in 2015.

Due to its nature, much of the improvisation we noticed were relatively easy to produce and cheap to maintain. Therefore, a set of slings used to assist patients in muscle strengthening is a good example for physiotherapists' improvisation. They built a net in the shape of an upside down 'L' situated above and alongside a bed or a chair. This net is then connected to a rope with a wooden connector, which allows for controlling the rope's length. One end of the rope is connected to a sling, while the other is connected to a metal hook. The hook can be fastened to any point on the net, and the sling fits on the patient's foot or hand. This makes it possible to adapt strength exercises for various positions, such as standing, sitting or reclining with varying levels of resistance – from strong resistance through the neutralization of all gravity and even active assistance. It is also possible to change the direction of the resistance or the direction of the movement assistance.

The initiator of the improvisation is the therapist. She benefits from two major advantages. First, **comfort and efficiency** – using the product is simple, quick and easy. Many therapists search for methods of reducing costs while increasing the benefit of the rehabilitation process, resulting in expanding the volume of treatment. Due to the intense daily schedules at the clinics, minimizing the time needed to develop the device is critical. Second, **modularity** – The patients' needs are amazingly varied. It is crucial to embed the ability to adapt a device to strengthen the patient's different muscles in various positions of the limbs and the body, according to the appropriate level of difficulty.



Figure 7: 'Slings' at the rehabilitation unit at Hadassah Hospital in Jerusalem

Conversely, the ability to improvise holds two major benefits for the patient. First, increasing the **volume** of the treatment – the improvisation allows for prolonged independent exercise sessions, following short and relatively simple adaptation of the device by the therapist. Longer training sessions improve the results of the rehabilitation process. Second, improving the patient's motivation and self-reliance – the ability to exercise independently, even in relatively early stages of the rehabilitation during which the patient is dependent and not ambulatory assists in increasing the patient's involvement in the process. It allows for the reduction of the dependency on the therapist. From a design point of view, therefore, improvisation is not a deviation but rather a systemic necessity, enabling a better therapeutic process.

The second example focuses on the reuse of baby strollers as a walking aid by patients. Contrary to the first example, this type of improvisation is not based on professional knowledge, but rather as necessity stemming from an understanding of the socio-cultural context in which the product is situated.



Figure 8: Classic walker

Throughout our shadowing research, we have noticed ultra-orthodox women using baby strollers as a substitute for the classic walker. This improvisation highlights both the strong communal bonds in the ultra-orthodox communities, as well as the drive to be perceived as healthy by the patient's surroundings. The variation of baby strollers enables the patients to choose a model more suited for her needs. While the reasons for preferring a baby stroller over a walker may result from either social or economic reasons, there is no obvious advantage for one over the other (except for the ability to carry objects in the stroller's lower compartment). Indeed, one must remember that the cornerstone of the rehabilitation process lies in the process of moving from injury to recuperation. The patients, therefore, progress in their efforts towards self-sufficiency and functioning in their daily routine. On closer examination we identify several important differences.

The walker reflects an aura of disability and incapability (the user is perceived as being cared-for), while the baby stroller broadcasts an air of health, independency and ability (the user is perceived as a care-giver). The design of these objects further emphasizes these differences. First, the walker's minimalistic aluminium rods create a cold and alienated aura, situating the patient as disabled. The tennis balls, used as an improvised way to softly and slowly walk, imbue the product with an air of ridicule. The baby stroller, however, is built from softer materials, rendering it a leisure or lifestyle accessory, rather than a medical product. These differences are mirrored also in the colour scheme of these products – a dreary metallic in the walker, versus an updated and varied fashionable colourful allure in the case of the baby stroller.

The structure and configuration of the products continue to highlight these differences as well. While the walker's structure is a symbol of austerity (to the extent of seemingly inattentive lack of imagination), the stroller is a symbol of en-vogue fashion and innovative sophistication. Finally, while the walker is sturdy and reliant, easy to fold (in the cases it does fold), and lighter, the walking is fragmentary and inconsistent; the stroller presents a smooth and consistent walking. In addition, while the walker leads the patient, the parent leads the baby nestled safely in the stroller. Therefore, while the stroller symbolizes the medical layer of the hospital, the stroller is situated in the socio-cultural layer.

Both examples, then, echo the necessity of improvisations in healthcare design. As we have seen, improvisation in these cases can generate from either a clear and immediate need, or from a gap between the original design and the design situation in the field. In the first example, the healthcare professional leads the process of improvisation, while in the second example, the socio-cultural attributes lead the patient to conduct a process of improvisation from the bottom upwards. Our main thesis is that since in various healthcare situations the actual design happens after the product has been used and modified according to the needs and constraints of the various design partners, designers should rethink the essence of healthcare design. Mainly, healthcare products should be originally designed with an embedded ability of enabling the various design partners to continuously improvise and change these products. This shift in agenda will prolong the life of these objects, as well as help all the players in each healthcare situation. The healthcare professionals will work more efficiently, the patients will earn more fitting products and the healthcare system will be able to treat more patients more efficiently. Therefore, healthcare design improvisation should be seen as a necessary opportunity, rather than a lack of imagination or indolence.

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Design, medicine, and pain: Connecting communities and practices

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ABSTRACT ONLY *About a third of Americans suffer from chronic pain—defined as any pain lasting more than 12 weeks—and many become dependent on opioids to treat it. The medical literature and patient narratives agree that the problem is not being addressed effectively. Research and experience also suggest that such a complex problem can only be addressed by a multidisciplinary effort, but that the greater the disciplinary range involved in a project, the greater the challenges are to simply making the project work.*

The presenter is leading a multidisciplinary design team to address these challenges, which include tackling opioid dependency and forging an effective team with participants from disparate fields. Specifically, we are working to improve patient-provider communication about opioids and chronic pain. This cooperative venture between a design centre, the university's medical centre, and a rural health clinic aims to create reference materials for clinicians, information materials for patients, and decision aids for clinicians and patients to use together in determining the best pain management options. Toward this end, we have brought together academics (from design, rhetoric, and communication), providers (from medicine, behavioural health, and pharmacy), and patient communities.

We are developing tools for both clinicians and patients that we are testing and refining. These tools are intended to answer a call from the Institute of Medicine of the National Academies for “new tools and metrics with which to define, diagnose, and monitor pain and its consequences, as well as for new approaches to treatment and prevention that are likely to result from novel and more interdisciplinary approaches to research” (“Relieving Pain in America,” 2011).

At Design4Health, I will discuss our collaborative design process and outcomes, along with insights about strategies we have developed for accommodating different disciplinary expectations and needs.

Keywords: Chronic pain; Shared decision-making tools; multidisciplinary approach; participatory design

Comparing Male and Female Experiences in IVF Treatment Using Journey Mapping

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ABSTRACT People that receive IVF treatment usually are a couple rather than an individual, this creates new challenges in understanding their experience. We use journey mapping to better understand male and female experiences as well as couple dynamics during IVF treatment. Observations, contextual enquiries, and interviews were done to assess the context and needs of couples during IVF treatment. Journey mapping was used to map the emotions, barriers, and points for improvement in each phase of the treatment for males and females. We extended the concept of an individual journey to a joint one combining the journeys of males and females to find opportunities for couple interaction and support during IVF treatment.

Keywords: IVF treatment, journey mapping

Introduction

Many healthcare organizations today focus on how to create healthcare technology that is meaningful for people. Our work in this domain is situated specifically in the context of fertility care. Infertility - the inability to achieve a successful pregnancy after at least 12 months of regular unprotected intercourse (Zegers-Hochschild et al. 2009) - has major psychological implications such as stress, feelings of depression, and relational problems. In this context, healthcare technology has the potential to help people in coping with their treatments and empower them to live healthier lives, both physically and mentally.

Depending on the cause of the reduced fertility, there are various possible treatments. We focus on people receiving in vitro fertilization (IVF) treatment. IVF treatment is one of the most stressful treatments; it can be challenging both mentally and physically. We develop an application that offers lifestyle support regarding physical activity, diet, mental wellbeing, and will give information about the treatment. The ultimate goal is to increase the ongoing pregnancy rate by reducing the early exit from the treatment and improving physical and mental health.

Reduced fertility is the main reason for heterosexual couples to seek IVF treatment, but also for same-sex couples and single people; IVF can provide a solution when sperm and/or egg donations are required in order to get pregnant. In this paper we specifically focus on heterosexual couples receiving IVF treatment. In this case, males and females experience joint and individual treatments, but the female is going through the major part of the treatment. The complex nature of their interpersonal relationship creates new challenges in understanding their treatment.

As these couples experience stress and changes in their relationships, their way of coping with this has implications for themselves and as a couple (Newton, Sherrard, and Glavac 1999). Generally, women report higher levels of stress than men (Greil 1997) and use different strategies to cope with infertility. Women more often seek social support, use escape-avoidance e.g. try to avoid or escape thoughts or feelings, and use positive reappraisal e.g. reconstruct stressful events as valuable or beneficial than men (Jordan and Revenson 1999; Peterson et al. 2006). Therefore, gender should be considered when planning interventions. The different experiences of males and females during IVF treatment has led to our research into the specific couple dynamics during IVF treatment.

Related work

Digital communication in couples

Prior research has already focused on several aspects of communication between partners in a romantic relationship. Scissors (2012) and Scissors and Gergle (2013) investigated how couples switch between communication channels in conflict situations and Scissors et al. (2014) researched digital communication in conflict situations. Computer-mediated communication can

provide useful strategies for initiating, managing, and resolving conflicts (Scissors 2012). These findings are relevant in the context of IVF treatment as couples have different coping strategies in dealing with infertility and this can lead to conflicts. Along the same lines, Scissors et al. (2014) outline potential benefits and drawbacks for apps that facilitate sensitive conversations in the context of IVF treatment. Using text messaging during a conflict can be harmful to a relationship, as it is associated with distancing behaviours such as delaying or ignoring responses.

In contrast to these potentially harmful behaviours He (2013) researched how technology can support intimacy and mutuality within a couple through collaboration in accomplishing collective tasks. Therefore, communication technology used during IVF treatment can improve relationships by documenting their collaborative experience and affection.

Finally, Branham et al. (2012) created a diary communication technology that facilitates information sharing between couples; They concluded that reflection can move partners' understandings of each other.

Evolution of healthcare

Healthcare has shifted from a paternalistic model in which care is done 'to' a person, to a model that is grounded in collaboration between caregivers and people that receive care (Charles, Whelan, and Gafni 1999; D'Amour et al. 2008; McMullan 2006); Both are involved actively in decision making and are sharing responsibility (Barry and Edgman-Levitan 2012). More recently, a holistic approach is being adopted, focussing on the people using healthcare services and their values, social situation and lifestyle. This approach is concerned with how people experience health problems as well as the evolution of diseases rather than focussing primarily on the evolution of diseases (Starfield 2011; Ekman et al. 2011).

In this context, the success of healthcare technology depends on how well it fits into the existing service and how well it is accepted by caregivers. For the technology to be accepted, it needs to create value for all stakeholders, not only the receiver of care. To facilitate this, service design is increasingly used to improve and innovate in healthcare (Bate and Robert 2007).

Journey mapping is a tool that is used in service design. It offers a framework for understanding the experience of people while they receive care (Trebble et al. 2010; Manchaiah, Stephens, and Meredith 2011), it describes the care pathway from the receivers point of view, and it shows how digital elements integrate into the care pathway.

In this paper we compared the male and female experience during IVF treatment by investigating their emotional responses, existing barriers, and points for improvement in each phase of the treatment. We extended the concept of an individual journey to a joint one, looking at both partners in a couple. Based on that, and on the existing insights in couple communication technology, we provide some new insights in how to facilitate communication and support in a couple app for people receiving IVF treatment.

Method

Our goal was to create insights that inspire the development of couple features for an application for people receiving IVF treatment. The work leading to this deployment consists of assessing of the context of IVF treatment and the needs in a qualitative study consisting of observations, contextual enquiries, and interviews.

Assessing the context of IVF treatment

In an effort to understand the context of people receiving IVF treatment we did observations and contextual enquiries. Seven observations of interactions between caregivers and people receiving IVF treatment were done in the Leuven University Fertility Centre (LUFC); These include three consults with gynaecologists, two consults with midwives, half a day of observations in the lab, and a demo of the online platform. The researcher made notes during and after the observations.

Eleven contextual enquiries with caregivers were done in the LUFC, the Centre for Reproductive Medicine University Hospital Antwerp (UZA), and with affiliated professionals. Contextual enquiries were done with two gynaecologists, four midwives, three psychologists, one relaxation therapist, and one dietitian. Contextual enquiries focused on stakeholders, important moments, lifestyle, and technology usage. All contextual enquiries were recorded and transcribed verbatim and relevant objects were photographed with consent.

Assessing needs of people receiving IVF treatment

To understand the needs of people receiving IVF treatment, seventeen semi-structured interviews were done with people receiving IVF treatment, focusing on lifestyle, couple interaction, and technology usage. Participants were recruited at LUFC, UZA, and via the main organization for people receiving fertility treatment that is active in Flanders, Belgium (De Verdwaalde Ooievaar). Participants could participate as a couple (5), or as an individual (11 females and 1 male). All interviews were recorded and transcribed verbatim.

The notes, photographs of relevant objects, and transcripts were coded and analysed using grounded theory as the underlying theoretical framework. NVivo, a qualitative software analysis tool was used to facilitate the analysis. This study was approved by the Social and Societal Ethics Committee at KU Leuven and the Ethics Committees of University Hospitals in Leuven and Antwerp.

Results

We focused on the context and needs of people receiving IVF treatment regarding couple interaction. While analysing our results we identified four main themes that are important:

Stigma for males. In society there is still a stigma on infertility; This is bigger when infertility is caused by males than when it is caused by females.

Different treatments. Males have a smaller role in the treatment than females. Therefore, males can be frustrated as their partner is dealing with the major part of the treatment, but there is not a lot they can do.

Support. Although females go through most of the treatment, there are opportunities for males to support females.

Different ways of dealing with infertility and IVF treatment. Females more often seek social support and males take more distancing approach.

Journey Mapping

Based on the analysis, we created user journeys to enhance our understanding of the experience during IVF treatment. We laid out the emotions, barriers, and points for improvement in each phase of the journey for males and females separately identifying and highlighting their unique needs. Finally, we combined the journeys to understand what the couple requires at each step of their treatment cycle and we identified opportunities for couple interaction and support.

Figure 1 shows the combined journey of males and females for one full IVF cycle. Typically, people go through multiple cycles as six cycles are reimbursed by health insurance in Belgium. Usually, in the preparation and embryo culture phase multiple ova (egg cells) are retrieved and multiple embryos are formed. Per full IVF cycle, usually one or two embryos are replaced and the surplus embryos are frozen for possible use in a subsequent partial IVF cycle (cryo).

Couple receiving IVF treatment - Combined journey for one IVF cycle

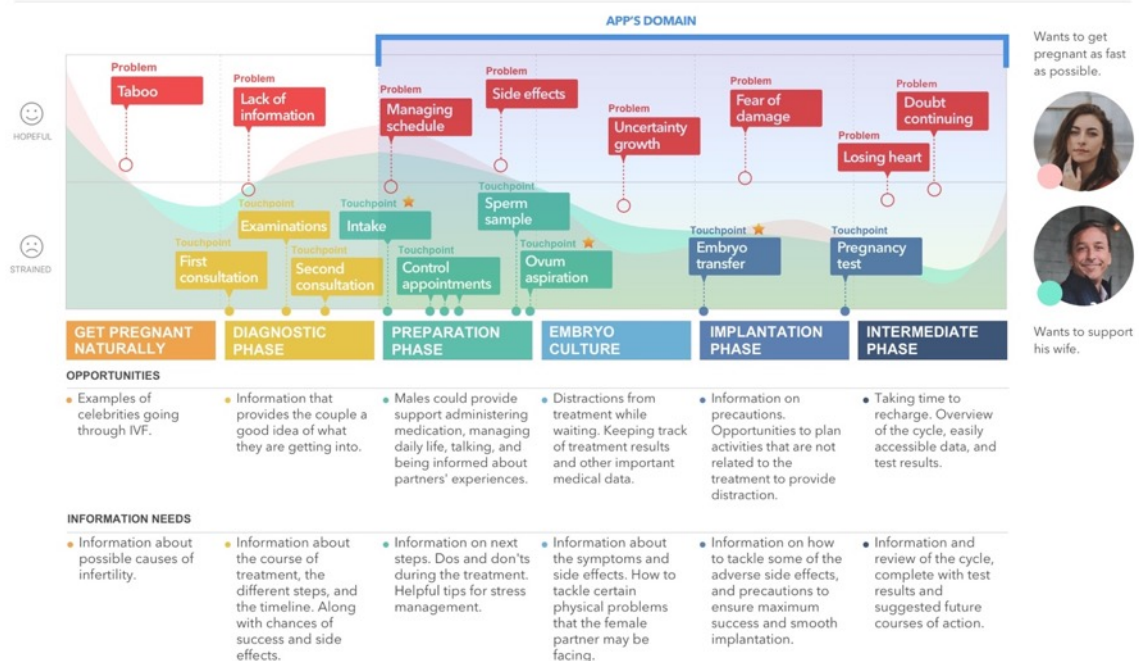


Figure 1: Combined journey for one IVF cycle

Looking at the two curves on the journey map, one can notice that the male and female go through the same ups and downs but the female partner experiences these ups and downs more strongly than the male partner.

In general, males have a smaller role in the treatment than females and because of this they feel frustrated as they can do little during the treatment. Related to this, we identified the first opportunity for couples in attending main appointments (intake, ovum aspiration, and embryo transfer) together.

In the preparation phase, for females emotional ups and downs can be a result of the hormonal changes induced to aid in the preparation phase of the treatment. The hormones also magnify smaller inconveniences that women experience in daily life and cause physical strain. On top of that, females have to go through regular check-ups in the hospital that are time constraining. These factors contribute to a higher fluctuation in the female partner's journey graph with respect to the male partner. In this phase the female has to go through many steps in the treatment. Besides providing the sperm sample, there is little that males are required to do and this can be frustrating. Here, we identified opportunities for the males to provide support by helping administering medication, helping managing daily life during the frequent check-ups that female has to attend and providing support by talking and staying up-to-date about the appointments and the experience of the partner.

For the couple, the hardest part is when there are no activities planned and the couple has to wait. For example, in the embryo culture phase there is a waiting period while embryos are being developed in the lab and in the implantation phase there is a waiting period after the embryo transfer. Here, we identified an opportunity for males and females to work together to create distractions from the treatment.

Conclusion and discussion

Although many general communication apps and technologies such as SMS, WhatsApp and social media such as Facebook are available, we believe that a dedicated app that provides guidance for treatment and also facilitates interaction and support between partners can add significant value for people during IVF treatment. It is important to note that both partners have a typical set of strengths and needs. In order to work as a team, they both need sufficient opportunities to use their strengths to address their partners' needs. Best et al. (2017) have already pointed out the potential of a couple intervention for weight loss in the context of infertility and obesity as couples support each other during everyday life and fertility treatment. A couple intervention could provide lifestyle advice as well as offer a module to improve social processes to facilitate behaviour change.

Journey mapping provides a tool for understanding the experience during IVF treatment. We compared and combined the journeys for males and females and analysed the differences. However, journey mapping is not without limitations. As fertility treatment is a highly dynamic treatment, timings and next steps in the treatment are dependent on the results in previous phases. This makes it a challenge to capture the treatment in a journey map.

Journey mapping allowed us to better understand couple interactions during fertility treatment and identify opportunities for couple interaction and support. We found several opportunities for collaboration between the couple: Throughout the treatment the couple could attend main appointments together; In the preparation phase males can provide support by helping administering medication, helping manage daily life during the frequent check-ups that the female has to attend, and provide support by talking and staying up-to-date about the appointments and experience of the partner; And in the embryo culture and implantation phase, males and females can work together to create distractions from the treatment.

Besides providing understanding of the experience of couples receiving IVF treatment, journey mapping helped us to visualize the interactions in a clear and clean manner and enabled us to communicate the complex situation to team members more easily. The results were used to inspire the development of concepts for couple features for our application, which is currently under development.

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Exploring posters as a probing tool to engage nurses in a development process

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ABSTRACT *In this paper, we explore the characteristics of posters as an efficient and effective probing tool for hospital nurse participation in the development of processes, services or products. The main challenge in this respect is the limited time and attention available to nurses during their work shifts. For this, we analysed the design and effectiveness of posters from earlier projects and used existing knowledge on probing for preliminary guidelines focused on design elements, context of placement, and fit with work process. We then designed a poster for gathering insights during nurses' work shifts into their administrative tasks and perceived relevance. To evaluate, this table poster design was consecutively placed on three nursing units in a Dutch hospital. Activities of nurses with the poster and necessary interventions were analysed and used for further insights into the characteristics of effective posters for this specific target group. The research raised new questions about how best to elicit nurses' participation during work shifts.*

Keywords: nurse, design probe, participatory design

Introduction

The 'Design for Nurses' research project focuses on involving the specific target group of hospital nurses in product and service development and procurement. We search and test which generative methods and tools (Sanders, Brandt, and Binder 2010) are efficient and effective both for nurses and for design researchers. Designers have a restricted amount of billable hours for projects, and during work shifts, nurses are fully focused on providing care (Sanders and Stappers 2012). This makes it difficult for nurses to step out of ongoing operational activities, for example for an hour-long workshop (Ostergaard, Karasti, and Simonsen 2016), in order to reflect on their experiences or to ideate. The challenge, therefore, is how to involve both nurses and designers in the design process in a way that is compatible with their working patterns.

The design of such a tool needs to be informed by its purpose and context (Sanders, Brandt, and Binder 2010). The paradox is that in order to design an effective and efficient tool for nurses that help gain insight on their workflow, we must already have (and be able to apply) knowledge of the nurses and their workflows. This conundrum necessitates an exploratory study, in which we not only design a tool to elicit insights and knowledge on the subject, but also to explore the effectiveness of the means of gathering the insights. In this paper we focus on posters as a participatory research tool for nursing units.

Method

This explorative study consisted of two parts. First, we analysed posters used in four earlier projects involving nurses at a Dutch academic hospital between October 2015 and November 2016, to uncover variables in design that influence the effectiveness of a poster. We used the remarks made on the posters, pictures of the used posters in their context, email of project manager and students, and journal notes made during that period for retrospective analysis.

The found variables were combined with literature and with practical knowledge of design probes and used as preliminary guidelines for the design and use of a poster for an ongoing project. The poster was placed in three nursing units successively, with time to make changes between applications based on initial results and feedback. During the period of placement, visits were made regularly to capture the progress by taking pictures of the poster in its context. Interventions intended to enhance the use of the poster were made by the researcher, nurse manager, or the nurses themselves. Interaction with nurses or others during visits was recorded in a research journal on a tablet. The entries were noted in a spreadsheet, with the dates of the pictures taken. This gave an impression of the rate of adoption of the poster.

The effectiveness of the posters is assessed by the 'momentum' of their input (i.e. the speed with which the nurses engaged and the extent to which they required prompting), the quality and quantity of their input, the observed actions, and also by the nurses' remarks on the use of the poster. The quality of the feedback was assessed subjectively, by the researcher.

Results

Retrospective analysis of posters

Four different poster designs in four different projects were analysed. These are shown in Figure 1 to 4.

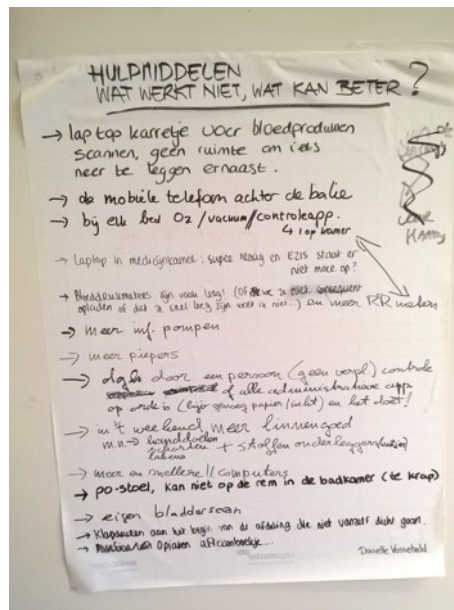


Figure 9: flipchart sheet (poster a) with short handwritten instructions for feedback on devices in general

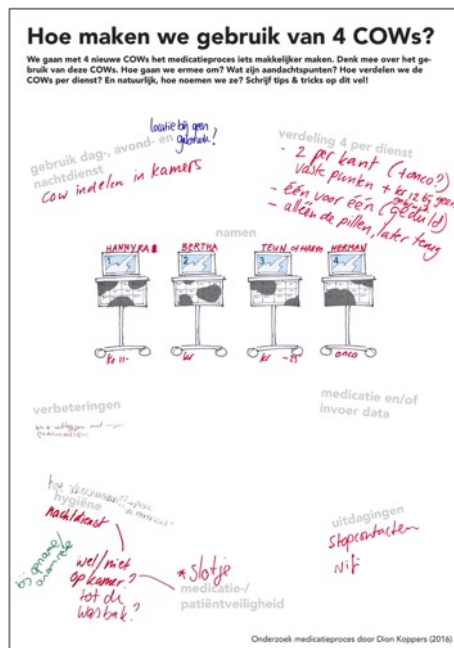


Figure 10: poster (b) on the effect of introducing four Computers on Wheels on a unit

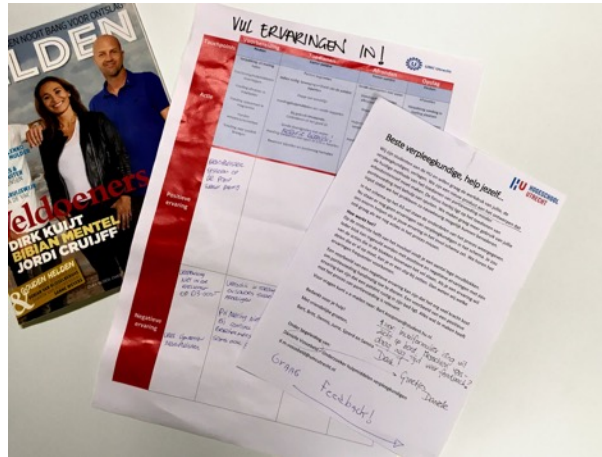


Figure 11: one of three copies of poster (c) on tube feeding on table



Figure 12: poster (d) on a possible layout of the nursing unit

Based on the analysis combined with existing insights of design probes (Gaver, Dunne, and Pacenti 1999; Mattelmäki 2006; Mattelmäki 2008; Sanders and Stappers 2012; Sanders and Stappers 2014), we tentatively identified groups of characteristics that can make posters effective participative research tools for nurses:

Design elements

The poster must be **inviting** and clearly **designed to be used**, with **enough space for writing**. High-quality materials and designs can be daunting to scribble on. **Use cues** and words as practical hints (Mattelmäki 2006) trigger input. Poster (b) shows clustering around the pre-printed subjects. A **first entry** by the researcher can lower the threshold for the nurses to contribute (Sanders and Stappers 2012). The flipchart sheet (a) was empty with handwritten instructions and thin lines which indicate use. It was fully filled after one week. The floorplan (d) looked more complex and already full. It attracted just one remark after two weeks.

Context of placement

The poster's physical location must be **in sight** ('in your face'-design) and **easily accessible** for writing. All posters were hung in the break room of nursing units, as this place is **most likely to be visited** during the shift. This room has couches, chairs and table(s), and is used by nurses for breaks, team meetings and instructions.

Posters (a and b) on the wall received relevant input. Two posters (c) remained empty after one week when placed on the whiteboard between other announcements. After placing them on the table, along with a personal oral and handwritten request by the researcher, the posters received input the same day.

Fit with work process

The poster should **not disrupt the work process**, **short and clear instructions** are necessary. Nurses' focus is on patient care, and they have little time for activities outside the primary process. Lengthy explanations as in posters (c and d) seemed to have a negative effect on use. The floorplan might also have been difficult and time-consuming to interpret. The **duration of placement** was for at least one week, so nurses from different shifts can participate.

Fit with the target group's characteristics

The poster should **match the characteristics of the nurses**, including their engagement with or level of knowledge on the subject. The general question of the flipchart sheet (a) could be interpreted on many levels and resulted in a wide variety of feedback which was not all relevant to the specified goal, but could be used for improvement of the unit.

Motivation

The poster should encourage a **sense of ownership** among the nursing unit, influenced by their perception of having an influence on the subject. This can be enhanced by the nurse manager, researcher, and/or peers **stimulating** the research. Personal contact with nurses resulted twice in valuable interaction. Poster (b) triggered a brainstorm among the available nurses when it was hung during the nurses' coffee break. The retrieval of one of poster (c) resulted in a conversation on the subject with a nurse on his break, leading to extra relevant insights. The announcement of the floorplan (d) in the 'weekmail' did not have any effect.

New poster design

We used an ongoing project on the administrative burden to design and test a poster based on the found characteristics. We gathered information on nurses' perceptions of the varieties and challenges of the administration and registration tasks they face (Michel et al. 2017; VvAA 2017).

The poster is based on day-in-a-life worksheets (Sanders and Stappers 2012) and consisted of a 24-hour clock (see Figure 13). The clock is divided into the three shifts, as a guide for specific tasks. Two specific moments in the nursing process which generate administration – the anamnesis (nursing assessment of a patient at hospital admission) and patient discharge – were placed as extra timelines on the poster. These timelines remained empty at unit one and this part was even folded back on day five. As the primary focus of the research was on the administrative tasks clock, we kept it like that, also with the other units.



Figure 13: poster design of nursing unit one

We initially devised the process to consist of three stages of one week which were designed to generate in-depth insights on tasks. The nurses were supposed to (1) list all administrative tasks, (2) assess the perceived relevance using red and yellow coloured sticker dots, and (3) indicate means and difficulty of the tasks. At unit two and three we combined the first two assignments in a one week assignment only. This merging resulted in needing a green dot to identify administrative tasks that were considered relevant, so we added this on the poster of unit three.

Context of placement

The posters were placed consecutively on the tables in the break rooms of the three units. The most distinctive feature of this poster design is the placement on the dinner table in the break room, like a large placemat. The rationale for this was that it is easier to write on a poster on a table than on a wall. Moreover, it was always in sight and 'at hand' for the nurses sitting at the table. The presupposition was that this table poster would ultimately gather more input than a poster on a wall.

On unit two, a nurse from the night shift had taken it to the nursing station. That night 19 entries were added (see Figure 14). At the end of day three, the poster was hung on the notice board and after that received three entries. On unit three a nurse immediately taped it to the table.

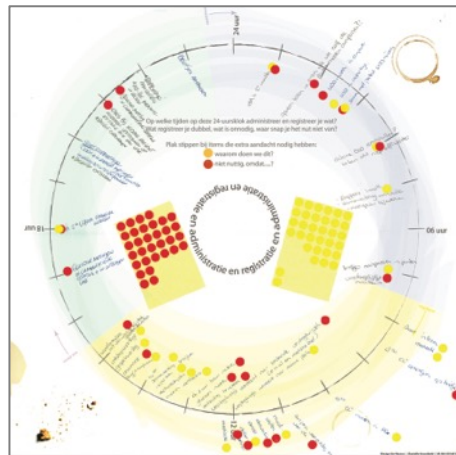


Figure 14: completed poster of unit two

Design elements

Coffee stains and cookie crumbs were printed on the poster as a 'use cue' that stains were 'allowed'. This idea backfired. On unit one a nurse assistant removed the poster to keep it clean because the first stain was already on it. We added a handwritten comment near the stain and printed a comment around the stain for the next two versions.

The poster was designed in accordance with the pre-identified characteristics of minimal text, enough space for writing, and clear intention of use. For unit one we had a short instruction on a separate sheet of paper. For unit two and three we wrote the assignment on the poster. The paper was plain, thick quality. Nurses could write on them with their pens, which they use for their administrative tasks.

Fit with work process

By placing it for a longer period (at least a week), most of the workforce of a unit had the opportunity to interact with the poster. Nurses could interact with earlier responses provided by their colleagues from other shifts, making it a collective effort of nurses.

Motivation

The poster was announced by the nurse manager via email the week before placement and/or during the first break. To attract attention to the poster, we designed space for the placement of 'stroopwafels', a Dutch treat.

The unit secretary of unit one reported that a nurse had taken it off the table because she did not want anything to do with it during her break. The secretary called it 'research-fatigue', as nurses already have to track so much for research purposes. Also, the placing of dots was done in a session organized by the nurse manager at the end of week two, as the poster did not receive input. Week three was therefore skipped.

At unit three most nurses mentioned that they had not read the 'weekmail' and assignment, so the researcher explained the poster. This triggered a discussion on several relevant topics, but no items were written on the poster. On day three the researcher intervened, adding one item to the empty poster and taping a small picture of unit 2's completed poster as a trigger. She asked a senior nurse to write the entries that had been mentioned on Monday (see Figure 15). After these interventions, nurses became more involved.



Figure 15: first entries poster nursing unit three

Effectiveness table poster

The poster in unit one got 45 detailed entries, including one by the researcher, evenly distributed in the first week, with a total of 52 after two weeks. The poster in unit two was filled with 43 detailed entries in the first 24 hours, with a total of 48 after one week. The poster in unit three remained empty for 48 hours and ended with 30 items, including one by the researcher and eight organizational tasks.

We also noticed that not all registration tasks were specifically mentioned. A nurse was observed answering an assistant physician three times to look for the requested information in the Electronic Medical Record (EMR) herself. It was also observed that a nurse entered the same measurements in two different fields in the EMR. Moreover, we needed additional explanation. One red dot, placed near the entry 'anamnesis', proved not to be a judgement on anamnesis in general, but on the fact that patient data was asked and registered twice during this process.

Discussion

The found characteristics of effective posters are interdependent. In our reflection on the process described above we focus mainly on how using a table poster is an effective tool for nurses.

As the poster was placed in the break room, nurses mostly interacted with it during their breaks, at which time we also had valuable interactions. We were, therefore, confronting them and engaging them in work-related issues during their moments of rest. This is questionable as work pressure is high due to the administrative burden (VvAA 2017). One nurse's solution – placing it at the nursing station during the night shift – may indicate a more appropriate location for such work-related research tools. This was impossible when it was taped to the table, which prevented it from being put aside.

Although the issue of administrative tasks entails a degree of urgency for nurses, it is also a wide-ranging and complex subject. It is however questionable whether nurses can, without hints, recall and reflect on all of the tasks during the shifts during their breaks. Triggering responses of nurses during their activities could have better results. The input is not complete, but interesting as a starting point for further inquiry. A follow-up is needed for comprehension of some results.

The idea of 'in your face'-design, by placing it on a table, was less effective in unit 3. As the break room had three couches, the table was less used. This may have had an influence on the lack of engagement with the poster. We also see a saturation in attention with units one and two. A week seems adequate for input from most nurses, and short enough to not get accustomed to and become invisible.

The distinct handwriting styles suggest that the posters were filled out by just a few nurses. It's unknown whether they did this by themselves or in cooperation with others, as in poster (b). Requesting a nurse to place a first entry as a use cue could also be more positive in a sense of ownership and as motivation. Extra personal, face-to-face encouragement and explanations of nurse managers and the researcher were needed to obtain relevant input for the project.

Conclusion

In order to explore insights regarding the working processes of nurses, table-top posters provide a promising tool. We have identified five tentative groups of characteristics of effective posters and their application in context, that could be useful for other nurse researchers to consider, apply and further develop. One thing is certain: just placing a poster on a wall in order to elicit insights is not going to be effective in a work environment where the focus is fully on operations and the research tool has to compete with many other requests for input. An active approach, with personal interactions, and moments for deepening questions and explanation by the nurses, can greatly enhance the effectiveness of posters for eliciting input on the design process.

Acknowledgements

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Design, architecture, pharmacy: making a difference to understanding anti-microbial resistance (AMR)

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ABSTRACT This paper presents the work of the AHRC-funded cross-disciplinary project, 'Information and Architecture in Persuasive Pharmacy Space: combating antimicrobial resistance' (IDAPPS) which is designed to support one of the strategic aims of the UK 5-Year Antimicrobial Resistance strategy 2013-18, how to 'improve the knowledge and understanding of antimicrobial resistance'.

The paper introduces the working methods and outcomes of work to consider how we can use space within a pharmacy to encourage people to engage with information about AMR and self-care; and how we can design information so it is understood, whether on paper or in digital form. The research methods included review and analysis of archival material relevant to presenting information about drug-resistant infections; hierarchical task analysis; and co-design workshops with pharmacy workers and users.

One of the IDAPPS research outputs was a competition, designed to reinforce the cross-disciplinary approach that we propose is key to the challenge of communicating about AMR. The paper discusses and shows examples of the ideas and prototypes that emerged from the teams of designers, architects, behavioural scientists, and pharmacists.

See also www.amrpharmacy.org

Keywords: information design, human factors, community pharmacy, indoor built environment, antimicrobial resistance, drug resistant infection

Design, architecture, pharmacy: making a difference to understanding anti-microbial resistance (AMR)

How can we use space within a pharmacy to encourage people to engage with information about drug resistant infections and self-care? How can we design information through effective use of space, so it is understood, whether on paper or in digital form?

This paper introduces a cross-disciplinary health communication project funded by the UK's Arts and Humanities Research Council. The 'Information Design and Architecture in Persuasive Pharmacy Space: combating anti-microbial resistance' (IDAPPS) project explores 'persuasive space' in the presentation of information, its situation within a community pharmacy, and how users interact with it. This supports one of the strategic aims of the UK 5-Year Antimicrobial Resistance strategy 2013-18, to 'improve the knowledge and understanding of antimicrobial resistance'.

The project aims included:

- to raise the profile of design in science communication
- to reinforce the value of the community pharmacy environment as a health information provider
- to develop the research and innovation capacity of architecture and information design professionals

Community pharmacies play a key role in delivering public health. They are spaces in which there are complex interactions and functions, where people wait for prescriptions to be filled or to see a pharmacist. We want to improve the efficiency of use of this space to encourage engaged and creative interaction with information about drug-resistant infections in different formats and modes. The project brings together academics and practitioners in information design, architecture, ergonomics and human factors, and pharmacy.

Inspiration for the project came from work done by Otto and Marie Neurath to raise awareness of, and support prevention of, diseases such as tuberculosis (TB) and malaria in the 1930s and 1950s. Their approach prioritized pictorial and schematic communication over words; their use of striking and effective images was based on consistent and carefully considered principles. They worked with their intended target audiences to find out how they might receive and use the information they encountered, including health educators, health departments and schools (see Burke, Kindel & Walker 2013: 342–53; Walker 2017). In the case of a series of charts explaining about TB, the Neuraths included instructions about how the display should be arranged in a church hall or similar public space, thus linking the information content with the space in which it was displayed. Our notion of 'persuasive space' incorporates ideas of using space in a community pharmacy and the use of space in document design to articulate structure and enable access to information.

Approach taken to the project

There are many experimental formats for developing interdisciplinary creativity. The IDAPPS model is based on architectural design studio as celebrated in the work of Donald Schön (1984). Sociologist Kate Pahl has taken 'design studio' beyond architecture and reused it in her work with diverse communities:

The studio is a conceptual space where groups form and grow things which emerge from something we recognise as working already. It involves a group of people who operate beyond the structures of the university and recognizes different types of expertise – all participants can emerge as 'experts'. It is adaptable and responsive to particular situations and is a space of action, process, and practice. (Pahl 2014)

This approach had been tested by the AHRC Creative Exchange Knowledge Economy Project 'Home Improvements' which aimed to bring together academia, practice and the housebuilding industry to develop interdisciplinary design research solutions to some of the problems endemic to UK housing (Samuel, 2018: 193). This project used a competition format to reinforce practitioner and cross-disciplinary engagement and to generate ideas. The competition format has two advantages. First, people who would not normally collaborate are drawn together and, secondly, the solutions are arrived at in a far shorter time than in a commercial environment.

IDAPPS followed the 'Home Improvements' project model, and we posted an expression of interest asking for teams of at least three members from different disciplines – architecture/built environment, information design, human factors/ergonomics, behavioural science, psychology, linguistics, biological science, pharmacy. The brief was for proposals to 'use "persuasive space" to encourage pharmacy users to think about anti-microbial resistance and to get involved in the fight against it. We want to raise awareness of self-care for colds and other ailments that don't require antibiotics.' This call resulted in 12 expressions of interest, from which we selected five teams to attend an Ideas Lab at the University of Reading. The aim of the Ideas Lab was to encourage collaborative working within and across teams and to provide contextual information to support the design process. We incorporated approaches taken in user-centred information design projects where patients, families, carers, health professionals and designers work together (e.g. Black et al, 2013; Cerne Oven and Predan, 2013), and by the integrating and participatory principles of human factors and ergonomics (Taylor and Hignett, 2014).

Collaborative and cross-disciplinary working

In preparation for the Ideas Lab and to find out how people used the Day Lewis pharmacy we were working with, we collected observational data for a Hierarchical Task Analysis (HTA) to map

possible customer (patient) pathways in the community pharmacy. HTA is a core Human Factors/Ergonomics method for understanding interactions among humans and other elements of a system. It is used to map systems by describing a task (e.g. collecting a prescription) as a higher-level goal with a hierarchy of superordinate and subordinate tasks. At each level of the subtasks, a plan directs the sequence and possible variance of task steps (Shepherd, 1998). The interactions were described as four stages of the pathways as shown in Figure 1 for the (1) approach to the pharmacy entrance and entry through the door; (2) journey from inside the door towards the shop/dispensing counter; (3) arrival and interactions at the counter; (4) departure, leaving the pharmacy. The use of plans allowed mapping of a variety of pathways, including purchasing medicines (over-the-counter and prescriptions) and other health and wellbeing shopping; seeking information for advice on medical conditions (especially when the GP surgery is closed or in an emergency when out of medication), getting rid of waste medicines, and using advanced NHS services including medicines review, flu vaccines, morning-after pill, stop smoking service, travel advice and NHS Health Checks.

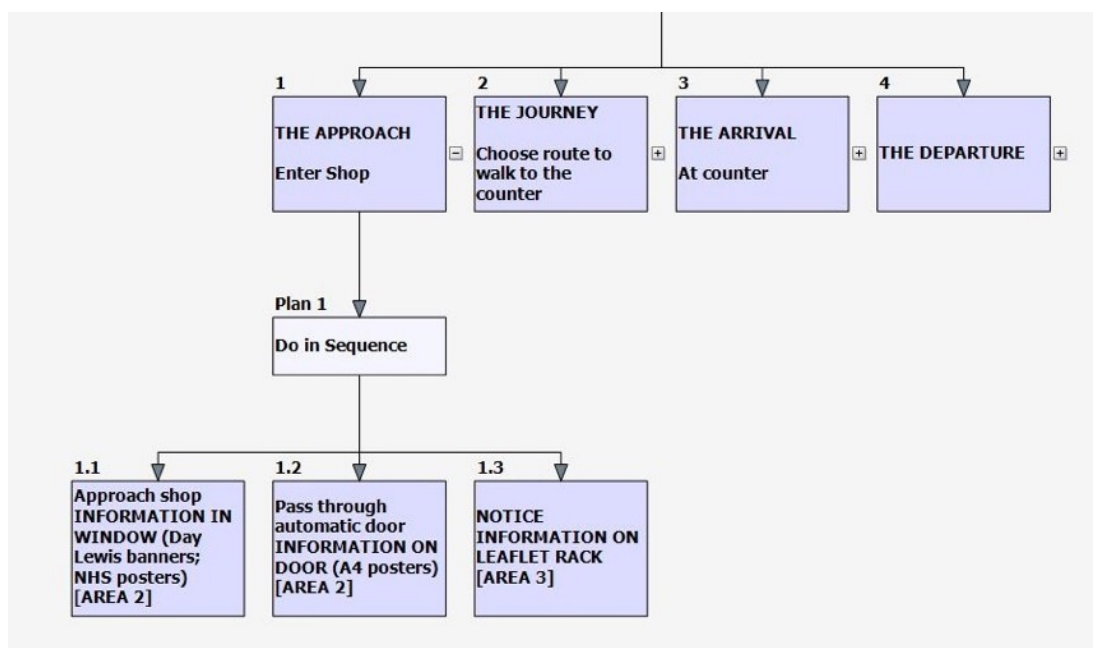


Figure 1. Hierarchical Task Analysis of interactions

We also undertook an historical review of printed ephemera to explore the kinds of graphic and verbal conventions used in the past to draw attention to issues such as personal hygiene, infection control and the dangers of particular diseases such as TB, malaria and diphtheria that were once considered major public health threats but are now becoming increasingly resistant to antimicrobials. We considered how techniques used in them might be transferable to presenting information about drug-resistant infections today (see Walker, 2017). Two charts produced by the Neuraths which attracted interest and discussion at the Ideas Lab are shown in Figure 2.

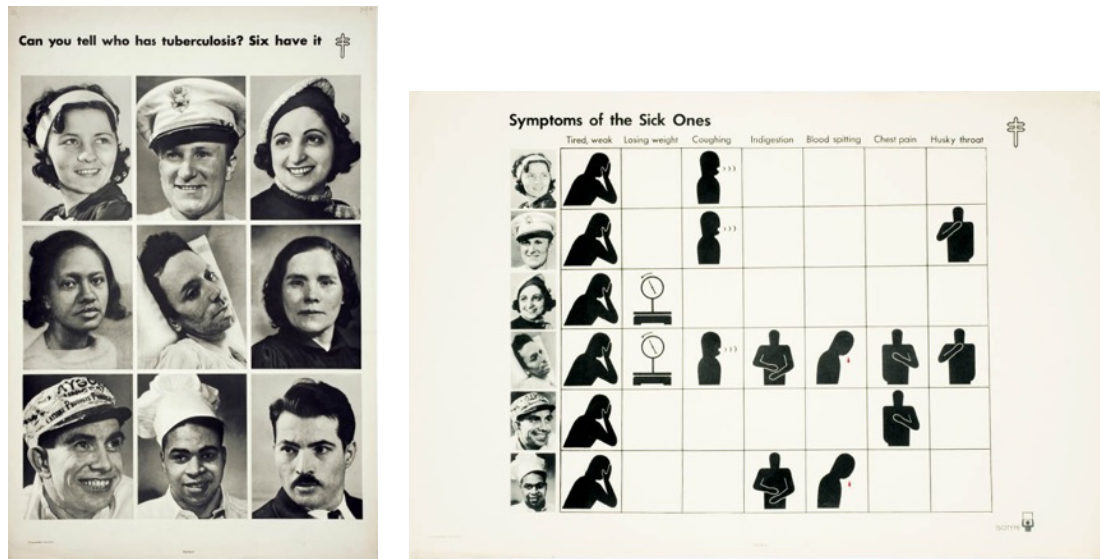


Figure 2 Two charts from the 'Fighting Tuberculosis' exhibition produced for The National Tuberculosis Association in the USA in 1938. Each chart measures 920 x 610 mm.
Otto and Marie Neurath Isotype Collection, University of Reading

The HTA and the archival review were introduced in a briefing workshop to define the parameters of the Ideas Lab, to design the competition brief and produce the call for entries for teams to participate in the competition. The workshop brought together an interdisciplinary group including the academic research team, project partners (including people who worked at the pharmacy where the winning design would be installed), members of the project advisory group and advisors from the architecture, design and pharmacy disciplines. This was important to ensure views, concerns and constraints from key stakeholders were shared in an open and collaborative way and potential issues addressed before the start of the competition.

We explored and discussed the community pharmacy context. This included findings from an online survey of local pharmacy users (n=19) to provide baseline information about their understanding of antibiotics and AMR, and their experiences of visiting their local pharmacies. The survey found pharmacy users had very good knowledge about antibiotic use and resistance but there were some misconceptions about AMR suggesting clearer messages about antibiotic resistance were needed. Pharmacy users were interested to receive health information about AMR and suggested pharmacists and GPs could offer such information. However, limited space and the lack of privacy within the community pharmacy were key barriers to opportunities for such conversations. Knowledge about our community pharmacy project partner, Day Lewis as a company and local information about the specific pharmacy store where the design was to be installed, was also shared and discussed.

At the two-day Ideas Lab a key component was 'team time' where the teams spent time sharing ideas and learning from each other's disciplinary perspectives. Comments included: 'Part of the nature of something like this is that it is not easy to work in interdisciplinary groups, and you are finding a language together as much as anything else.' And '... one of the best things that has

come out of today, is that we are all trying to understand each other, and that makes for really interesting conversations'. The team sessions were interrupted by 'show and tell' presentations where ideas were shared and discussed with the whole group. The competition teams had access to the expertise of our pharmacy partner, Day Lewis, and pharmacy users joined the Ideas Lab on the second day to respond to emerging ideas and to offer suggestions. Each team visited the particular pharmacy we are working with in Woodley, Reading.

After the Ideas Lab the teams had four weeks to work up a proposal – which they were asked to present as two A2 boards, with a written (or spoken) rationale and any models or artefacts that might be relevant. The project team, the manager of the Woodley Day Lewis Pharmacy and members of the project advisory board acted as judges and selected two proposals to take forward. These 'winning' proposals will be installed in the Day Lewis pharmacy in Woodley, Reading during summer 2018, where we will ask pharmacy users about their understanding of antimicrobial resistance after they have experienced the installations.

Competition outcomes

The competition format has enabled rapid generation of different approaches to considering how space in community pharmacies can be used to facilitate engagement with information about antimicrobial resistance. Each of the five solutions is relevant and feasible and offers potential for future work.

The value and benefit of cross-disciplinary working is well-known. Using a design-led approach that includes user-centred, collaborative working is not new. But in the context of this project the combination of disciplines, including architecture/built environment, user-centred design, human factors and ergonomics, pharmacy practice and behavioural science was an unusual mix that appears to have been particularly relevant in considering 'persuasive space' in a community pharmacy. A key design driver was the involvement of the manager of the Day Lewis pharmacy that we were working with. He provided invaluable context, including about the particular demographic in Woodley. Beyond the local Day Lewis environment, the overarching Day Lewis philosophy of the healthy living pharmacy and their promotion of this through staff support and training provided invaluable insight about the kinds of interaction likely between pharmacy users and staff.

Introducing the notion of 'persuasive space' alerted the teams to the ways in which people moved around the pharmacy and how the constraints imposed by a particular indoor built environment were affected by Day Lewis's requirements for product placement, and the arrangement of shop fittings – the tension between retail and health care as noted by Rapport (2009), and between educating and advising pharmacy users, and dispensing prescriptions described by Pronk et al (2002) in relation to pharmacies in Holland. The consideration of these and related issues was evident in the proposals submitted by the teams. Ideas around 'inside' and 'outside' space featured in three of the proposals: the idea of a garden environment where people can sit;

graphics on the pavement to instil curiosity as they walk towards the pharmacy; and looking in from the outside at an interactive, outward-facing installation. Consideration of how people moved around within and used the internal spaces was evident in all the proposals. Some non-design professionals in the group realised that design had a part to play in encouraging thinking about ways of solving problems and devising solutions (as opposed to something that was brought in at the end of a project as a presentational tool).

Already, the IDAPPS project is raising the profile of how community pharmacies might be used to encourage people to engage with the dangers of, and prevention of, drug-resistant infection. The next steps will be to consider the feedback from pharmacy user and pharmacy workers about the two winning solutions, examples of which are shown in Figure 3 below.



Figure 3 Examples from proposals from the two winning competition entries. See www.amrpharmacy.org

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A reflective tool to consider notions of healthcare community participation in design

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ABSTRACT *This paper aims to interrogate the meanings and assumptions related to the term 'participation' in design with and within healthcare communities. Drawing on a PhD case study that focussed on patient engagement in spinal cord injury (SCI) rehabilitation, it aims to contribute to this discussion with a novel framework that considers the epistemologies of both healthcare and design.*

The proposed framework is informed by well-known models in this area, including Arnstein's Ladder of Citizen Participation (1969), critiques the hierarchical nature of such models, and expands on them by proposing temporal considerations of a design process. The framework encompasses a variety of healthcare community stakeholders at different stages of the design process, and prompts consideration of the role of the designer within such co-design practices.

For the author, the act of populating this framework facilitated a much deeper understanding of how the design methods employed facilitated meaningful participation (or not) within the PhD study. It does not presume to fully define the nature of participation, rather it hopes to provide a starting point for other designers and healthcare practitioners to adapt it to their own contexts, and facilitate collective reflection within and between the fields of design and healthcare.

Keywords: Co-design, Participation, Theory

Introduction

From the foundations of the civil rights movements in the 1960s and 1970s, the notion of public involvement has gained increasing interest in a multitude of fields and contexts, including policy-making, design and healthcare. One of the most influential theoretical frameworks emerging from the former around this time is Arnstein's Ladder of Citizen Participation (1969), shown with additional definition in figure 1 below:

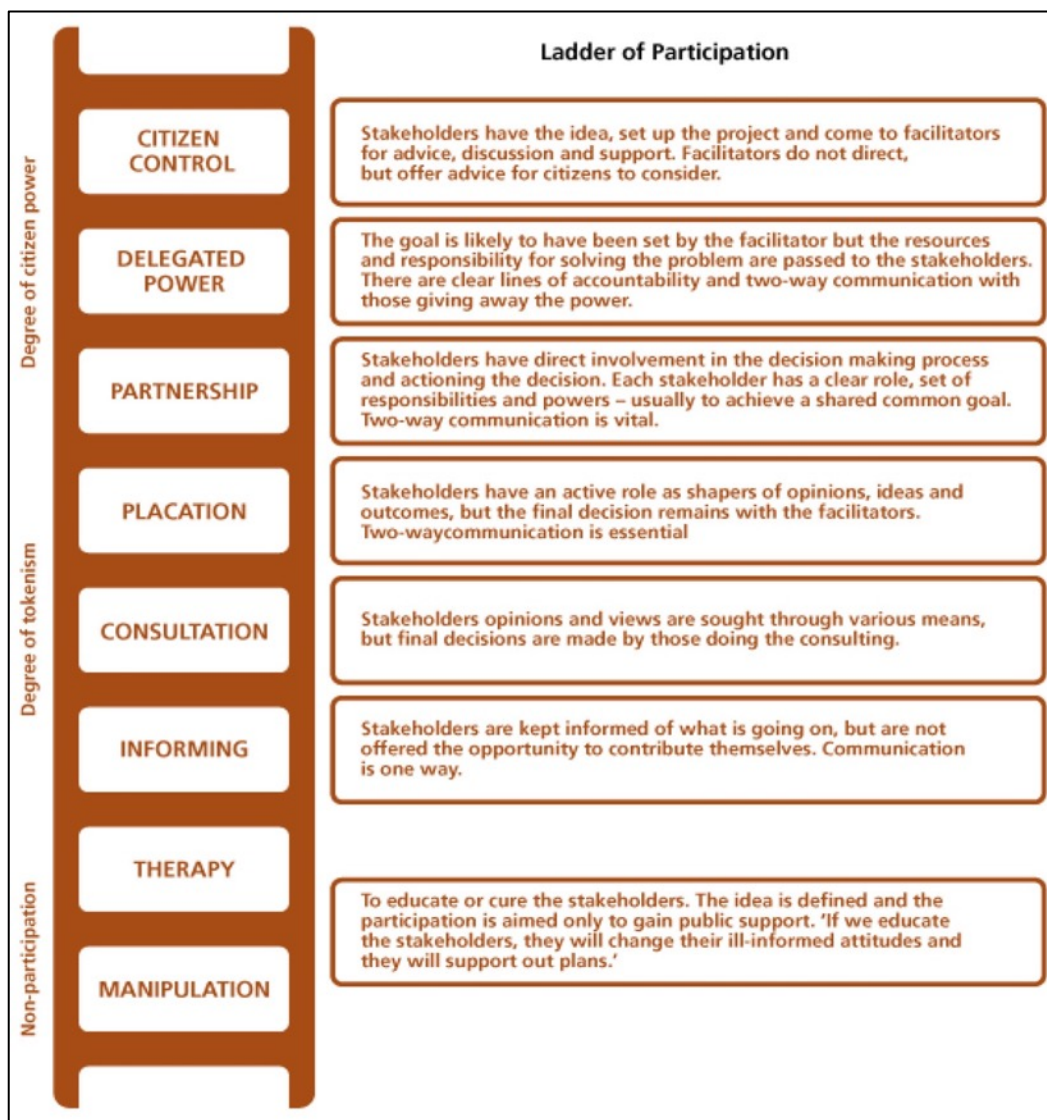


Figure 1: Arnstein's Ladder of Citizen Participation (see Arnstein 1969), with additional detail given by Rosier (2013).

By demonstrating multiple, increasing gradations of 'participation,' Arnstein aimed to convey an understanding that whilst participation is power, some forms of 'participation' (shown in the lower sections) do little to renegotiate traditional power structures. She argues that 'participation

without redistribution of power is an empty and frustrating process for the powerless' (ibid 216), and frames citizen's active involvement in decision-making as the key contributor to 'citizen power' (see the 'partnership' rung of the ladder in figure 1).

Arnstein's model is still influential today and has been adapted to a variety of contexts (as will be discussed below). However, it is not without criticism. Arnstein herself admits that the reality of participation often doesn't fit within the neat rungs of the ladder, and that key factors affecting distribution of power are omitted, such as race, gender and socio-economic status. More recently, the ladder has been critiqued for its inability to reflect on or relate to the context in which it is used, nor does it provide guidance into how participation can be progressed within a project (Collins and Ison 2006). Moreover, the hierarchical nature of the model doesn't account for the multiple ways in which people can participate, or how this may change over time (Tritter and McCallum 2006).

Clearly, the notion of participation is complex. This paper will continue by exploring how participation is currently conceptualized in the fields of health and design. For brevity, the scale of participation realised in practice in these fields is omitted (but more fully explored in Wheeler 2018).

Participation in Healthcare

Within the field of healthcare, particular attention has been paid to the traditionally paternalistic nature of doctor-patient relationships since the 1970s. There has been an increasing desire to put patients (and, more recently, their families also) in the centre of their own care, and in the development of healthcare services. Theoretical frameworks that conceptualise this 'participation' as a variable to be measured are well-suited to this context, given that research within healthcare predominantly emerges from the scientific paradigm. It is unsurprising, then, that Arnstein's Ladder remains influential in this context, as shown in figure 2 below:

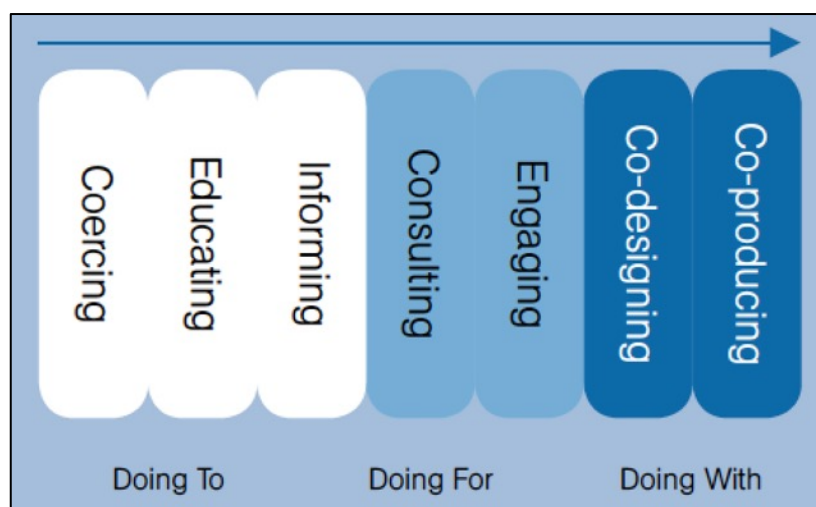


Figure 2: The New Economic Foundation's (NEF) alternative 'Ladder of Participation' (Slay and Stephens 2013).

In their adaptation of Arnstein's classic framework, NEF have chosen more contemporary language related to healthcare and design. The definitions of each level at the 'Doing To' and 'Doing For' territories are largely comparable to Arnstein's, however their use of 'co-designing' rather than 'delegated power' suggest a more collaborative approach between designers, healthcare professionals and healthcare service users. NEF's inclusion of the term 'co-producing' (defined as 'a relationship where professionals and citizens share power to plan and deliver support together, recognising that both partners have vital contributions to make,' [Slay and Stephens 2013, 3]) also addresses notions of power within the specific healthcare context.

Participation in Design

Notions of participation in Design originated in the Scandinavian workplace democracy movement of 1970s (Simonsen and Robertson 2013). Since then, Participatory Design (PD) has developed a rich history and plethora of tools to facilitate and encourage user participation in the design process. Although the field originally focussed on ICT interventions, it has since inspired a range of co-design approaches (as shown in figure 3 below) and expanded into multiple complex contexts, such as healthcare.

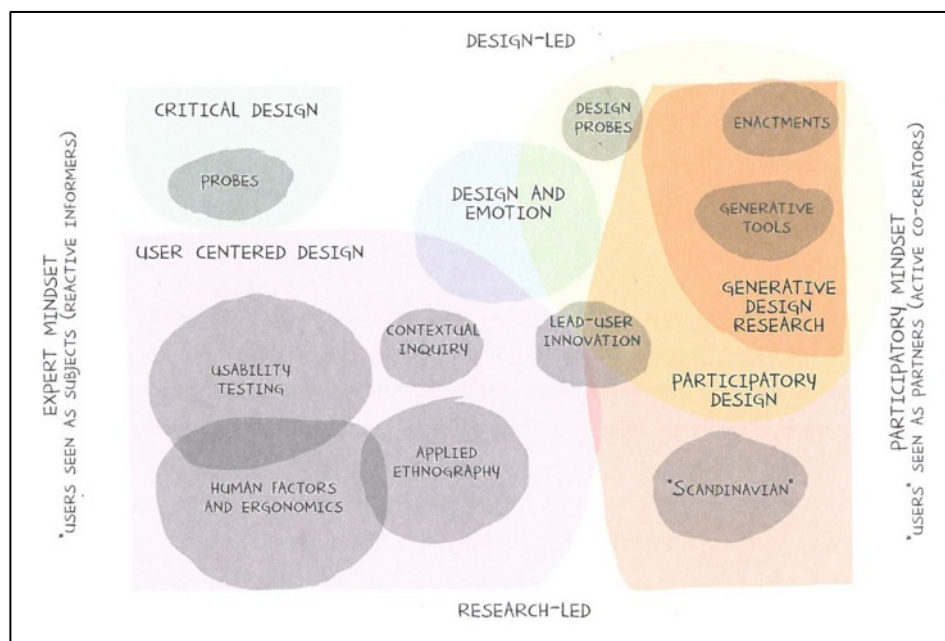


Figure 3: A 'Topography of Design Research' (Sanders and Stappers 2012, 19).

In contrast to healthcare's traditionally positivistic paradigm, the field of design operates with social constructivist approach, which places an emphasis on understanding people's lived experiences and their social interactions. Rather than seeking universal truths, Design aims to engage with the 'messy' nature of reality and the complexity of problems within it. Perhaps due to this complexity, it has been argued that the field of Design has been less successful in reflecting on the nature of participation that it affords in the new contexts it operates within, and with the wider

range of (potentially vulnerable) participants it seeks to engage (Kraff 2018). In addition, some argue that the field has privileged the earlier stages of the design process (or 'fuzzy front end') and had 'less focus on the back-end of the development process,' (Almqvist 2017, 2524).

In response, Kraff proposes the using context-specific tools for reflection (see figure 4 below), that can 'give visual form to complex situations, highlight differences between groups and indicate how participants' positions alter over time,' (2018, 60).

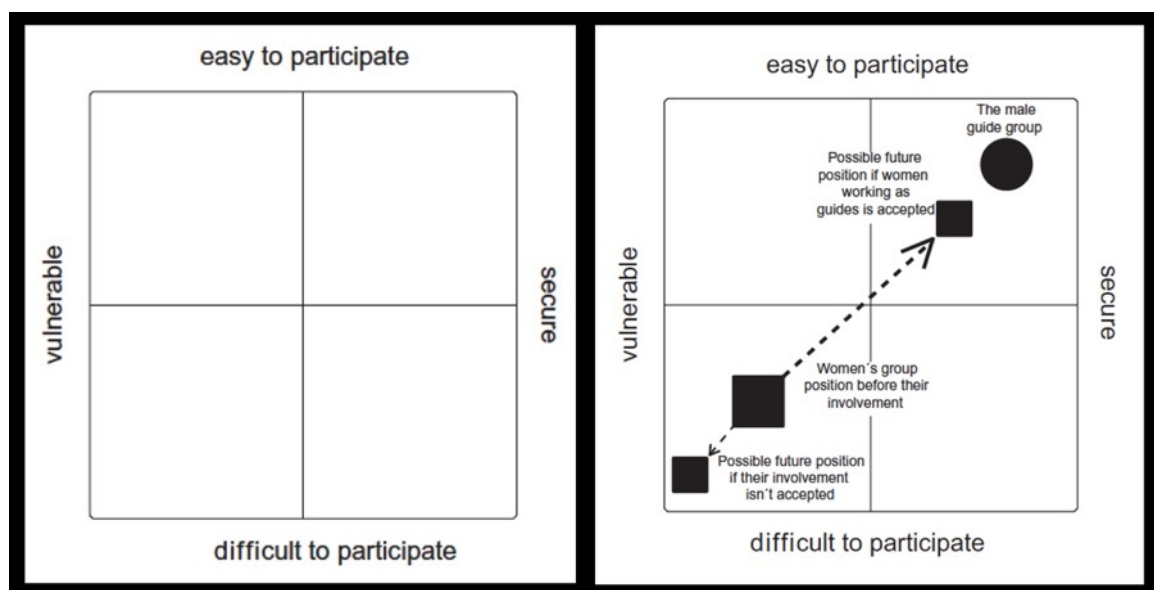


Figure 4: Kraff's tool for reflection (2018). The completed example, shown right, was used to reflect on a project exploring tourism in a Kenyan fishing village community, and demonstrates how male and female participants' standing in their community could have been affected by her study.

Whilst the tool is simple, the arguments underpinning Kraff's model and its temporal considerations were useful in reflecting on the PhD study described in this paper.

Reflecting on Healthcare Community Participation in Design

Context: PhD Study in a Spinal Injuries Unit (SIU)

The participatory framework proposed in this paper was created during a PhD study which aimed to explore and enhance patient engagement in spinal cord injury (SCI) rehabilitation, with and within a host SIU community (Wheeler 2018). The author was embedded within the host SIU, and engaged inpatients, outpatients, family members, 'front line' SIU staff, senior SIU staff and associated SCI charities. Following a year-long, mixed-method contextual review, it was decided that inpatients and SIU staff would be engaged separately in subsequent co-design activities, in order to protect their ongoing therapeutic working relationships (given that co-design activities can be critical of current situations, or in this case, patient pathways). Since PD generally holds

face-to-face interaction as the 'gold standard' of collaboration, this raised questions over the nature of participation afforded to each SIU community stakeholder group. As such, the literature from both healthcare and design (and the models discussed above) were reviewed in order to develop a visual exploration of how the SIU community participated over the course of the PhD study. The findings and implications of this exploration are discussed below.

Outcome: A Participatory Framework that Bridges Healthcare and Design

To enhance its clarity and acceptability to medical audiences (as a key group that this PhD study aimed to contribute to), the notion of a 'ladder' was retained as an anchor point in the framework. Whilst this is placed on a y axis and retains a concern with how power is distributed between participants (as in Arnstein's original ladder), NEF's terminology was used for its relevance to the PhD context – in particular the notions of co-production of healthcare services. Inspired by Kraff (2018), the framework also adds a temporal dimension along the x axis, to account for how the design project (and therefore modes of participation) evolved over time. To better reflect the context in which it was used, and particular concerns of the project (i.e. engaging stakeholders separately for ethical reasons), each stakeholder group in the SIU community is represented as occupying individual (although sometimes overlapping) territories (inspired by Sanders and Stappers [2012]).

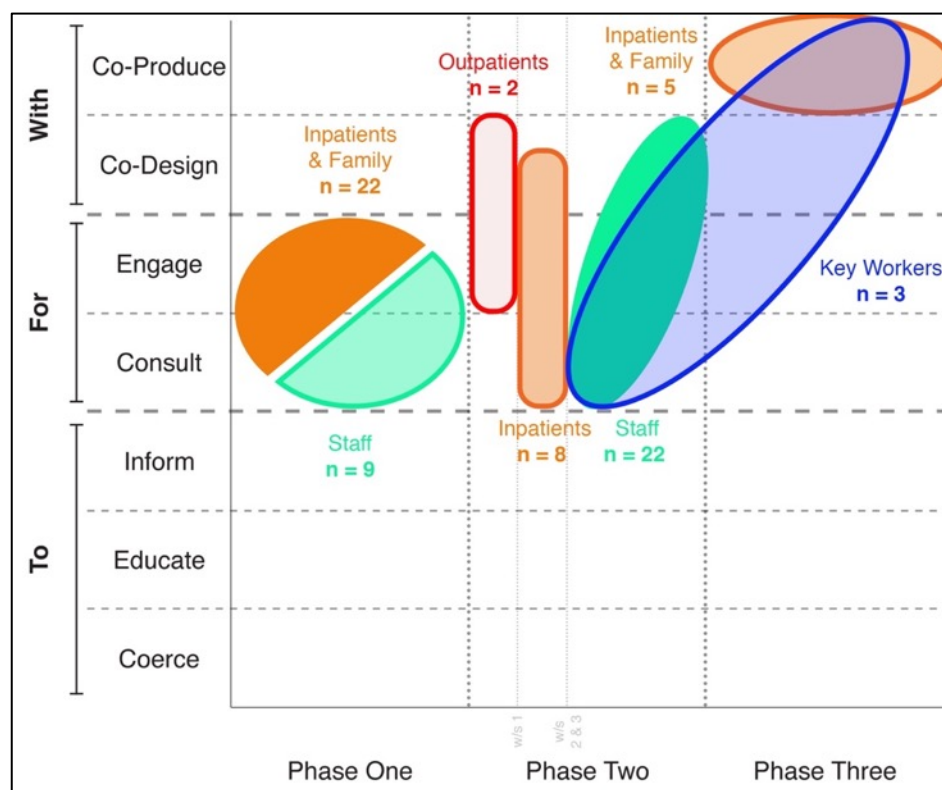


Figure 5: A visual exploration of how various stakeholders in a spinal injury unit participated in a service design project.

Phase One

In Phase One, inpatients, family members and staff members were invited to informal, questionnaire-led semi-structured interviews to understand their perspectives on the focus of the PhD; the Goal Planning Meeting (where a patient, and possibly a family member, meets with their multidisciplinary rehabilitation team approximately once a month, to set rehabilitation goals and review progress made to date). The quantitative and qualitative data from these interviews were used by the author to generate a set of initial rough prototype materials that could potentially be used in a GPM to enhance patient engagement within it.

As the SIU community engaged in Phase One were not invited to make decisions that affected the design process (other than deciding what their priorities for change were), both participant groups are placed in the 'Doing For' levels of the ladder. The territories cover both 'Consult' and 'Engage' levels to reflect how some participants had a more 'active role in shaping the opinions, ideas and outcomes' (Rosier 2013) than others (i.e. by giving their opinion on the current patient pathway as well as suggesting alternative formats).

Phase Two

Throughout Phase Two, outpatients, inpatients and SIU staff were engaged (in that order) in a series of co-design workshops to iteratively develop the initial rough prototypes. As can be seen, outpatients are placed slightly higher on the ladder than inpatients, as the former made significant changes to the prototype materials. Some members of the inpatient group also made decisions to affect the prototypes, whilst others preferred a more passive role in the co-design sessions, and this is reflected in the longer, slightly lower position of their territory. The SIU staff territory is shown to reach higher levels over time, depicting the change in the nature of design decisions made when enactment activities were introduced in later workshops.

Phase Three

Phase Three entailed the implementation, testing and evaluation of the co-designed intervention in the rehabilitation pathways of three inpatients. A separate (blue) territory has been given to the three 'Key Workers' (staff who take ownership of coordinating a patient's multidisciplinary rehabilitation team, and typically chair GPMs) who were involved in the Phase Two and went on to lead the implementation of the co-designed intervention. Staff and patients used the co-designed intervention autonomously, without any input from the author (other than one 'design-in-use' meeting with Key Workers, see Wheeler [2018]), and as such their work is placed in the 'Co-Production' levels of the ladder.

Discussion

What does this show?

Whereas 'ladder' types of participation frameworks aid reflection on the power dynamics affecting a project, they can present an overly simplistic and static view of the messy reality of human social interaction. Complementing this 'ladder' with an x axis in the framework above allows for nuanced understanding of how a design project can evolve over time – providing a 'snapshot' overview at a quick glance, or a more nuanced understanding with closer review.

In this case, stakeholder groups were given separate territories on the framework according to their role in the SIU community (i.e. inpatients, outpatients, family, staff). However, this technique could also be used in other contexts to acknowledge the role of race, age, gender, etc., in the power dynamics affecting participation, addressing previous critiques of 'ladder' models (Arnstein 1969). In addition, the suggestion that stakeholder territories can occupy multiple levels on the ladder addresses other concerns that hierarchical models do not accommodate the multiple ways in which people can participate over time (Tritter and McCallum 2006).

By mapping the PhD study onto this framework, the author can argue that the approach taken was not concerned with 'Doing To' the SIU community, and that as the design process progressed, it moved the project from 'Doing For' to 'Doing With' the community. As such, the framework evidences the value of long-term collaboration between designers and healthcare communities. In addition, it provides a visual description of the importance of having a core group of clinical staff 'champions' to help lead the implementation of co-designed interventions. In this case, the three Key Workers (shown in blue on the framework), bridged the gap between co-designing in Phase Two, to autonomous co-production in Phase Three.

What are the implications for Design in Health?

For Independent Reflection

The framework above hopes to go some way to acknowledging the messy reality of participation and to respond to recent calls for more situated (almost anthropological) understandings of design practice in context (Suchman 2011). The process of creating and reflecting on frameworks such as this forces designers to reflect on the co-design tools or activities created, what was achieved and how their practice could be improved. For example, by changing the opacity of the stakeholder territories on the framework to reflect the numbers of participants in each group, the author was confronted with the question of whether outpatients and inpatients (total n=10) were as influential or had as much power as SIU staff (n=22) in Phase Two. This in turn highlights the role of the prototypes (initially developed by outpatients and inpatients) in carrying the patient 'voice' forward through to these later stages.

For Group Reflection

Kraff argues that a visual tool 'enables collective reflection and a shared understanding between researchers, since it allows people to see each other's thoughts, rather than just hearing or reading them,' (2018, 61). As such, it could be argued that the framework could be used as a tool for healthcare staff and designers to share and co-develop their understandings of how the former were engaged in the project. Doing so could draw on healthcare practitioners institutional and experiential knowledge, extending their participation beyond the project, into developing the practice of Design in Healthcare.

Implications for Design Practice

The y axis of this framework forces designers to consider what type of power was afforded to participants by the co-design process they facilitated. As such, the act of populating such a framework may respond to recent discussions in the PD literature calling for designers to critically reflect on the influence they have in participatory projects (Light and Akama 2012).

Through the addition of an x axis, the framework allows designers to reflect on how participants' involvement evolved (or not) over time. As such, it may encourage designers to give equal consideration to the (often neglected) later stages of the design process (Almqvist 2017).

Conclusion

The fields of Healthcare and Design each have their own history and (somewhat contradictory) conceptualizations of 'participation.' To facilitate mutual learning, frameworks to reflect on healthcare community participation in design projects are needed that are understood and respected by both fields.

In the context of a Design PhD hosted within a Spinal Injury Unit, the author proposes such a framework that, whilst being somewhat specific to this context, could provide inspiration for other Design researchers working with and within healthcare communities. By complementing Healthcare's need for definable 'measures' of participation with Design's ability to engage multiple stakeholder groups in an emergent, evolving manner, the framework aims to address contextual and temporal critiques of existing frameworks of participation. This framework aims to inspire designers to create their own visual representations of their participatory practice, to support reflective conversations with themselves and their peers. It also aims to invite healthcare communities into this conversation, extending their involvement not just in the design project, but also in its evaluation; including their voice in the development of the field of Design for Health.

Acknowledgements

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Child-led, Creative Exploration of Paediatric Incontinence

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ABSTRACT *This paper describes a novel collaboration between a health science initiative, a MedTech Co-operative, and a university design research department alongside a group of children with incontinence, their parents and siblings. This collaboration hoped to inform the development of technological interventions specifically aimed at supporting paediatric incontinence.*

Together, we used a range of bespoke tools to creatively and collaboratively explore questions of 'What are your main challenges? How do you currently address them? And how would you like to address them in the future?' These tools aimed to place the children as the experts in the rooms, reflecting on their wider life (i.e. their hobbies, friends, family) and took an asset-based approach to highlight the skills and resources they already leverage to address their personal challenges. Later, ideation activities were used to empower the families as inventors to highlight and address any unmet health needs. Central to each of the activities was the aim to reframe a traditionally 'taboo' topic as something that is safe, and even fun, to explore through creative means.

This study concludes that by using context-specific, sensitive and creative tools, children from a range of ages can (and should) be included in setting the agenda for future healthcare technology development, even in topics that are traditionally difficult to discuss.

Keywords: paediatrics, co-design, incontinence

Introduction

Background

Incontinence, a lack of voluntary control over urination or defecation, can occur for a variety of reasons, on a spectrum of severity, and is more commonly associated with older adults. However, approximately 900,000 children and young adults are affected by continence issues in the UK (BBC 2015), whether as a result of medical problems or not having undertaken correct toilet training. Although children represent a smaller percentage of the population with continence issues, the impact upon them should not be underestimated. The effect on a child's wellbeing at school, risk of bullying, and potential lack of confidence in participating in social or sporting activities may have lasting implications for the rest of their lives. Despite this, incontinence is not a popular subject of research.

Aim of the Work

IMPRESS (Incontinence Management & PRevention through Engineering and ScienceS) is a research project funded by the Engineering and Physical Sciences Research Council (EPSRC) and the National Institute for Health Research Healthcare Technology Co-operative (NIHR-HTC). Their aim is to encourage more engineers and scientists to work on researching new technologies for incontinence. In previous work, IMPRESS identified a significant gap in provision for children with incontinence, when problems persist beyond toilet training or pre-school age.

In response to this need, IMPRESS organized a Family Day event to learn about the lived experiences and unmet needs of children living with incontinence, and their families. The aim of this workshop was to inform future innovation of relevant medical technologies in this area, to better support these families in their day to day lives. To support this work, they invited the input from Devices for Dignity (a Sheffield-based NIHR-HTC who aim to catalyse the development of new medical devices, healthcare technologies and technology-dependent interventions within the NHS) and Lab4Living (a Design and Healthcare research department within Sheffield Hallam University, who use creative means to facilitate shared understanding between multiple stakeholder groups in a range of healthcare contexts) to develop a co-design workshop to explore these topics.

Research Questions

To meet the aims of this work, several research questions were developed that took an asset-based approach to enquiring into children and family's lives, and the impact of continence issues upon it:

- What are *your* main challenges of living with continence issues?

- How do you currently address these challenges?
- How would you like to address these challenges in the future?

The co-design activities developed to answer these questions sought to draw on participants' creativity, as well as support them in sharing their existing knowledge and coping strategies – each key principles of co-design. The efficacy and lessons learned from conducting these activities will be the focus of this paper, rather than the clinical insights generated from them (which can be found at tinyurl.com/ya3wa6mx).

Challenges

Both the context and the community involved in this work presented particular challenges for co-design. As described above, the impacts of incontinence can be complex and far-reaching (including the lives of parents and siblings), making it a difficult topic to explore and generate a meaningful understanding. In addition, children may find it harder to articulate their needs due to less developed language skills, and the particular sensitivity of the subject. As such, the design of this Family Day workshop focussed on creating a safe space for children and families to 'open up,' to trust the facilitators and to draw support, not embarrassment, from meeting new families on the day.

Developing the Workshop Plan

Prior to designing any workshop activities, an initial literature review was conducted exploring how children are currently engaged in co-design activities. According to the literature, there are mixed opinions of whether children should be expected to participate in service, architectural or product development (Newman and Thomas 2008), but if so, their involvement should be fun (Baek and Lee 2008). Whilst there are several theoretical frameworks available that discuss the roles available to children in such activities (Druin 2002; Guha et al. 2005; Hart 1992), we found the following key lessons useful for our work:

- Play is the most natural form of expression for children (Baek and Lee 2008, 174).
- Activities that focus on self-expression, rather than 'right/wrong' activities, are effective (van Rijn and Stappers 2008).
- Due to a potentially shorter attention span, longer activities for children should be built of short steps that build upon each other (Baek and Lee 2008).

However, very few examples of co-designing with children in healthcare contexts could be found (see Hussain and Sanders 2012); instead the literature largely focusses on the development of school environments or learning resources.

To begin planning the workshop, members of the IMPRESS team briefed colleagues from Devices for Dignity and Lab4Living on the context of childhood incontinence and key areas of focus for the workshop. From this, the first author drew on the literature review findings and previous experience of engaging children in co-design activities to develop a draft workshop plan. The authors then met and iterated the workshop plan over several months to consider; the age range (and therefore attention span) of participants; the presence of siblings and parents; and logistics of the venue. Once a plan was established, a professional illustrator was commissioned to further develop bespoke tools for the activities, to help facilitate the workshop and support the dissemination of the findings (as will be discussed below).

Conducting the Workshop

A range of tools were developed to support activities of reflection and communication of unmet needs, followed by ideation of how these needs could be better met. The morning of the 'Family Day' was dedicated to primary school-aged children and families, and the afternoon to secondary school aged-children and families. As such, the tools were adapted to each age group. For clarity and brevity, this paper will focus on the morning session, with younger children (aged 4-11).

The co-design activities aimed to be ambiguous enough (i.e. not overtly focussed on the medical condition) to be fun for siblings to take part in as well as the child with incontinence. This aimed to capture the unique perspectives of siblings, but also to avoid singling out the child with continence issues unnecessarily. The attending parents and a group of healthcare professionals were asked to help facilitate the activities with younger children, whilst the authors 'floated' around the room, providing additional help and instruction as needed.

A selection of key tools and the lessons learned from them are discussed alongside the three original research questions below.

Research Question 1: What are your main challenges?

It can be easy to consider our 'health' in terms of symptoms, so we found it useful to begin the workshop by prompting children and families to reflect on the continence issue's impact on their wider lifestyle. This was facilitated by a quick 'warm up' activity shown in Figure 1:

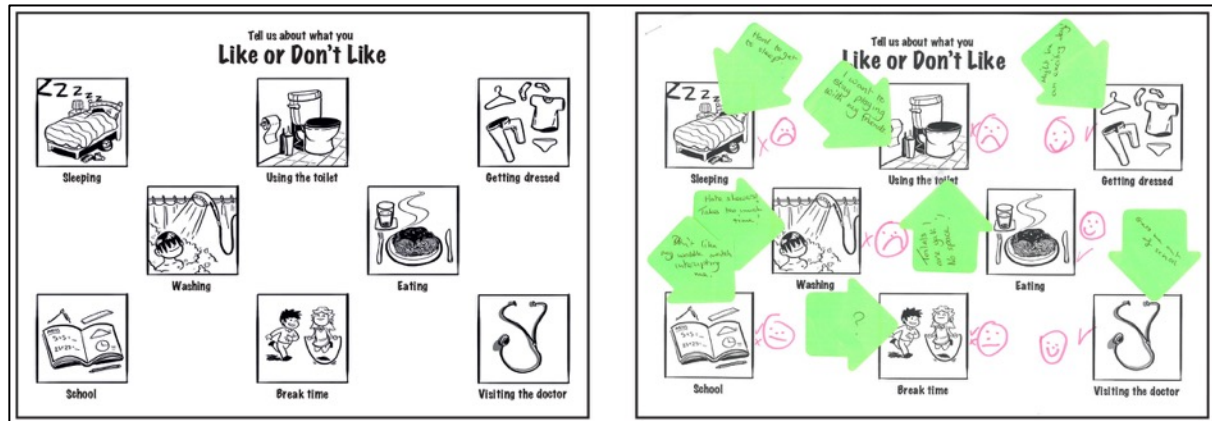


Figure 1: The Like/Don't Like activity (approximately 10-15 minutes) asked children to first draw a happy or sad face by each activity, then to use Post-its to tell us why their continence impacts these activities (see Gielen 2008).

This short and easy to understand activity was motivating and provided a 'quick win' for children. It also gave facilitators an idea of the children's interests and key issues, to inform their conversations with them as the workshop progressed.

Next, we continued our reflection in more depth with the 'Map my World' activity, shown in Figure 2 below:

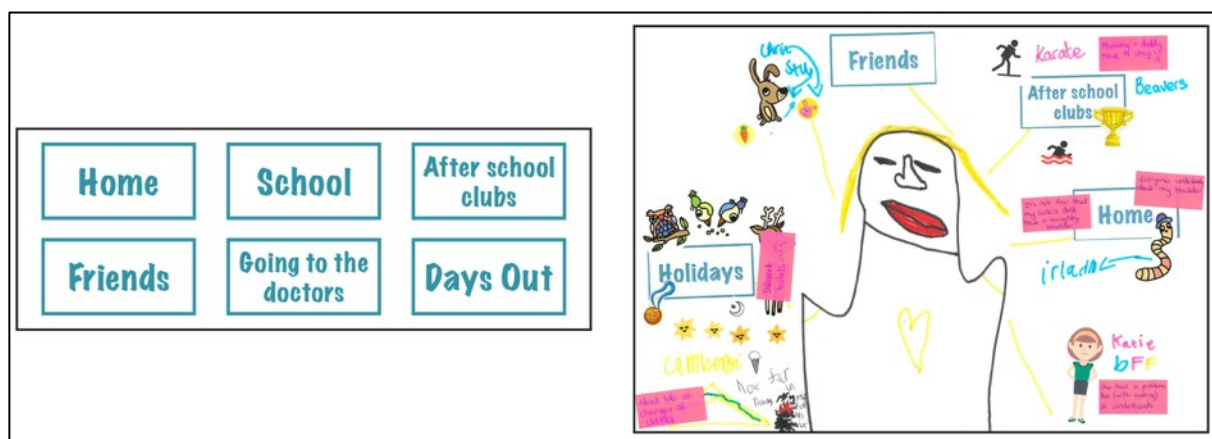


Figure 2: The 'Map My World' activity

After drawing themselves in the centre of the page, and choosing from a set of prompt cards (words such as 'Home,' 'School,' 'Hobbies', and 'Friends'), children were asked to use a range of stickers, printed images, and their own drawings to create a collage of what was important to them. This aimed to reinforce notions of self-expression, treating them as people, not symptoms. Following this, children and parents were asked to use Post-its to tell us about the 'challenges' they encounter in the different areas of their life. We chose the term 'challenges' rather than 'problems' to infer an issue that can be addressed, maintaining a positive, productive tone to the

activity. This opened up the agenda for conversation, and gave facilitators an insight into children's unmet needs alongside the relevant context and/or reasons, whilst also preparing participants for the next activity.

Research Question 2: How do you currently address these challenges?

Continuing the 'Map My World' activity, families were asked to revisit the challenges raised and annotate them with ways in which they currently address them. This provided an opportunity to learn about their current coping strategies, which may in turn inspire medical technology innovation in this area. This activity placed participants in the position of experts, and created a forum for families (who are rarely brought together) to learn from each other too. We found this was also an empowering activity, as it highlighted to families how well they are doing, and how much they have already overcome themselves.

Research Question 3: How would you like to address these challenges in the future?

Changing the tone of the workshop from 'what is' to 'what could be', idea generation was facilitated in a playful way with the 'When I grow up' activity, shown in Figure 3:

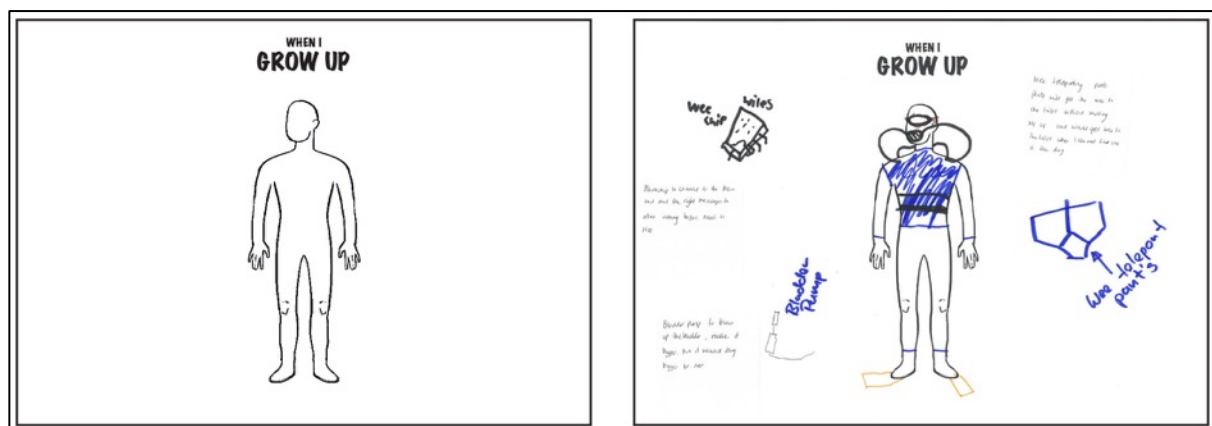


Figure 3: Children were first asked to draw themselves as a grown up, adding details to show what job they will do, if they will have pets, etc. Then, they were asked to imagine they are an inventor in the future, and draw any gadgets or equipment would they like to overcome the challenges they have now, to get to that future.

This activity led to 'blue sky' ideas which catalysed interesting conversations. For example, one child's 'teleportation pants' invention, which automatically transported any 'accidents' without anyone knowing, led to discussions on his fears about children at school finding out about his continence issues. We feel such candid conversations, and inspiration for technology innovation,

may not have arisen from traditional, questionnaire-based research techniques, nor leave scope for children to prioritize their issues.

Discussion

This paper has demonstrated how health- and design-based approaches can work together to explore children's perspectives on complex healthcare issues, in their own words. We found that short, easy to complete activities which build upon each other and focus on playful forms of self-expression were effective, in accordance with the current co-design literature.

We propose a contribution to the literature in this area with our use of an additional activity that occurred in parallel throughout the workshop. Our professional illustrator created a mural that was responsive to the outcomes of the workshop activities as they progressed, in real time. The mural was based on an island, made of three territories that corresponded to our three original research questions:

- 'Challenge Swamp' linked to 'Research Question 1: What are your main challenges?'
- 'Solution Forest' linked to 'Research Question 2: How do you currently address these challenges?'
- 'Idea Island' linked to 'Research Question 3: How would you like to address these challenges in the future?'

The illustrator would move between groups of children and their families during the workshop activities, take notes on their insights, and draw simple representations of their issues and current/future solutions in the corresponding territory, as shown in Figure 4 below:



Figure 4: The Island Mural

In this way, the progress made across the island acted as a 'guiding narrative' throughout the workshop and a clear indicator of progress (see Dindler and Iversen's notion of 'fictional inquiry' 2007). The mural also provided a level of abstraction that aided creativity – by framing the activities around this playful idea we aimed to create a more comfortable atmosphere for children who may not be used to talking to adult strangers about sensitive health issues. With this in mind, the mural was also a useful tool for children to volunteer ideas for each of the territories anonymously, and could frame their suggested ideas as something that might be useful for children with continence issues generally, rather than for them personally.

At the end of the day, the mural became a clear, tangible outcome that the children could see that they had contributed to – they had completed a 'journey' across the island together and we had listened to their expertise. The mural also created a 'quick win' in terms of research findings, by providing an overview of key issues, coping strategies and unmet needs. In turn, this overview helped to inspire and inform a six-page comic, which incorporated the findings of the day (and some of the children's original drawings) in narrative form. This helped to distribute the research approach and results in a participatory manner that is understandable to the children and young people involved (see Figure 5 below and visit tinyurl.com/ya3wa6mx to download the full comic).



Beyond workshop methods, events such as this must give careful consideration to logistics. We received a high turnout of children and family members by conducting the workshop on a Saturday (to reduce clashes with work or school commitments) and by researching appropriate venues. We chose a medical history museum as a 'neutral space' (i.e. not a hospital or school) that offered additional fun activities before and after the workshop (giving more incentive for parents to travel and providing alternative entertainment for siblings). We also argue that such a high

response rate (60 registered participants from across Scotland, England and Wales) highlights a need for further research in this area.

Finally, we argue that facilitators of events dealing with sensitive healthcare issues of young people should endeavour to tailor the approach they take with each child. We found that each family framed and talked about the child's continence issues differently, and it is important to respect this. Terminology can also be picked up and adopted, for example, one child referred to their urinary incontinence as their 'naughty bladder.' Above all, it is important to engage children as children – unique individuals who aren't defined by their healthcare condition.

Conclusion

Through our Family Day co-design workshop for children with continence issues, alongside their parents and siblings, we have demonstrated a range of creative tools that facilitate meaningful, sensitive, and even fun ways of discussing healthcare needs. We have found that discussing 'challenges' alongside current and potential future solutions is an empowering way to discuss healthcare issues, and is likely an approach applicable to a range of contexts with children and adults alike. In addition, the use of a mural that evolves according to the children's input was a motivating method of demonstrating progress through the workshop, highlighting the value we placed on their contributions, and a useful tool to facilitate further discussion on a potentially 'taboo' topic. We argue that children and young people can, and should, play a key role in defining the future of medical technology innovation, and that creative, collaborative methods can help to ensure such innovation is responsive to their lived experiences and future aspirations.

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CAREABLES: Co-designing Open Healthcare

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ABSTRACT *Digital fabrication labs and maker spaces have emerged across the globe in recent years to become local community hubs for a wide range of Do It Yourself-activities. In parallel, open source information and tools have triggered grassroots solutions in healthcare. Patients, their families, carers, health professionals and designers started to create personalized 'open' healthcare solutions in a bottom-up way. Within Made4You, an international innovation project, we aim to link local communities of citizens with disabilities, their families, and healthcare professionals with makers/designers to establish collaboration between these separate communities to develop open-source interventions under the name of Careables. Careables are driven by a methodological commitment towards co-design of 'open' healthcare solutions, involving all relevant stakeholders. Key to co-design is that people become creators, not only users of innovation. In our case, patients, their families, healthcare professionals and designers are involved in the co-design process as experts in their specific environments, together with makers, who are experts in the use of digital tools, such as 3D printers, laser cutters, etc. Part of the project is to critically reflect on and question the potential of co-design of 'open' healthcare solutions.*

Keywords: open design, healthcare, communities, DIY, fablabs

Introduction

#WeAreNotWaiting. A group of concerned parents decided to develop an open source, Do It Yourself digital self-management tool that helped them better manage the blood sugar of their children (diagnosed with Type 1 Diabetes), as commercial systems were not providing the feedback they needed to monitor and support their children. Inspired by a vast amount of online open information on software and hardware development, they took on a role as developer and produced remote access to blood sugar information of their children. A Facebook-post brought these parents in direct contact. With *Nightscout* (Continuous Glucose Monitoring in the Cloud) they devised a tool - through reversed engineering of an existing commercial technology – that allows parents remote monitoring of their child with diabetes. By developing *Nightscout* citizens have taken matters in their own hands and started a revolutionary movement in digital social innovation in healthcare. So, be impatient! (Lee et al. 2016)

Nightscout is a shining grassroots example of citizen driven, social digital innovation. Over recent years citizens, including many patients and caregivers, became impatient and started developing personalized devices and tools that provided support to meet their needs. Access to the Internet, open source information and digital tools empower citizens, including patients, caregivers and healthcare professionals, to improve the self-management of their disease or to develop aids that support them in coping with daily hindrances of physical limitations. A growing number of grassroots solutions saw the light of day: from open source hand prosthetics, 3D printed writing tools to support kids with physical limitations, to add-ons for wheelchairs, and everything in between.

Bottom-up digital social innovations

Bottom-up digital social innovations are on the rise, including in healthcare. Innovators, users and communities in healthcare are starting to collaborate by using digital technologies to co-create knowledge and solutions for a wide range of needs. These innovations are at a scale that was unimaginable before the rise of the Internet (Bria et al. 2014). Examples that add to this experience are *eNable*, where an owner of a 3D printer used this technology to print a hand prosthesis, based on a prototype from the early 1800s (Knochel et al. 2018). His technical information was published open source and adopted by a growing group of 3D printing engineers that provide people in need with customized 3D printed hand prosthesis. Or *OpenAPS* in which a female engineer with Type 1 Diabetes developed a DIY Open Artificial Pancreas System based on existing approved medical devices in combination with commodity hardware and open source software and it was designed primarily for safety, simplicity and interoperability with existing treatments (Lewis et al. 2016). These examples have been developed thanks to open source and low-cost open hardware, Internet of Things, crowdsourcing of knowledge and skills and access to digital fabrication tools.

An inspiring example has been the co-production and replication of a tricycle for Lorenzo, a 6-year-old who suffers from a complex neurological pathology that makes most daily actions

difficult (see: figure 1). The patient organisation TogetherToGo teamed up with Milano's Fablab Opendot to engage in co- design, customization and rapid prototyping to produce a tricycle with reduced cranks, ergonomic saddle, support for the back and adjustable handlebar (see: figure 2, 3 and 4).



Figure 1: Tricycle Lorenzo

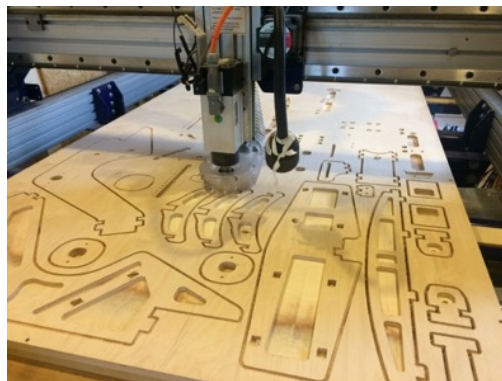


Figure 2: Using fablab to produce the tricycle



Figure 3: Detail of the tricycle



Figure 4: Lorenzo on his tricycle

The 3D model is customized for Lorenzo, but can be quickly adapted to the needs of other children with different disabilities (see: figure 5), using personal digital fabrication. In the

Netherlands a replication of Lorenzo's bike has been made in the Fablab of WAAG, showing the potential of 'open' healthcare solutions (see: figure 6).



Figure5 : Tiziano and Luca taking measurements for new custom size bicycle for Viola



Figure 6: Replication of Lorenzo's tricycle

Increase accessibility healthcare solutions

Open source solutions as mentioned above, increases the accessibility of healthcare solutions. This accessibility towards healthcare fits into the framework on integrated people-centred health services, as published May in 2016 by the World Health Organization (WHO 2016). The WHO proposed a fundamental shift in the way health services are funded, managed and delivered through empowered and engaged citizens within communities. The WHO envisaged, in this framework, that all people have equal access to quality health services that are co-produced in a way that meets their life course needs and respects social preferences. The ambitious health services should be safe, effective, timely, affordable and of acceptable quality. The framework can be adapted to all countries whether high, medium or low income as well as mature or fragile health systems. Open healthcare solutions, like *Nightscout*, illustrate the WHO framework and deliver health services that meet the needs of citizens, empower and engage communities and are co-produced by the users.

With the emergence of fabrication laboratories - over 1.000 labs worldwide - and makerspaces, the possibilities to use digital fabrication techniques, such as laser cutters, Computer Numerical Controlled (CNC) milling machines and 3D printers, have become readily available to create opportunities to allow citizens and communities to develop and produce personalized solutions and innovations in healthcare and have the ability to change the production process in healthcare.

Enable citizens to co-design

The mission of the European funded project Made4You is to enable citizens to co-design and deliver personalized, people-centred health solutions, using digital fabrication (see figure 7).

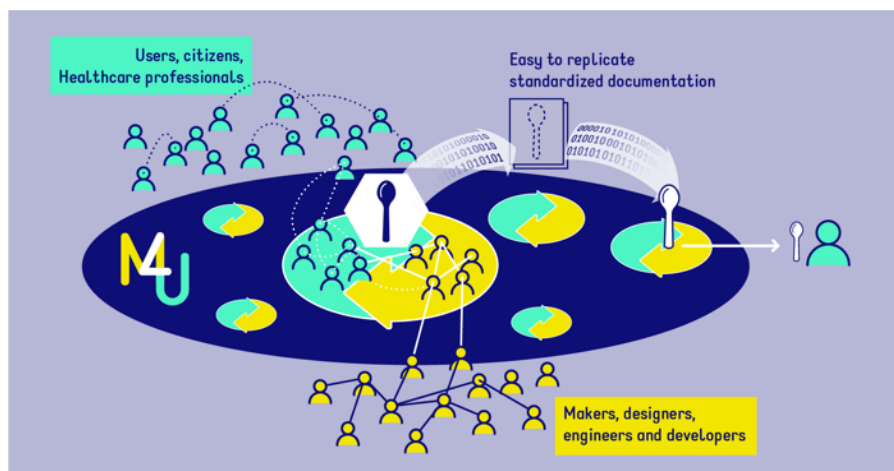


Figure 7: Made4You Vision for Personal Making of Open Healthcare solutions

To establish such an ecosystem of open healthcare solutions an open and online platform is required that:

- Connect existing communities of makers, engineers and fabricators with communities of citizens (including patients) and healthcare professionals;
- Co-design open healthcare solutions for citizens facing physical disablements, and for healthcare professionals to improve the healthcare services they provide;
- Improve access for citizens to grassroots healthcare solutions via co-design methods and open standard documentation, and provide them the tools to become active innovators;
- Establish a wide user-base open and dedicated platform to share and exchange open healthcare solutions as well as co-design experiences;
- Collect available existing solutions and make them more accessible via open standard documentation on the platform.

Made4You's ambition is to establish **the central hub Careables for citizens worldwide to find open healthcare solutions** that can be customized to adapt and self-manage physical conditions to their own needs and wishes, and understand how to make solutions real (see figure 8).



Figure 8: The Careables platform

The online platform is the linking pin to different user groups, from people with physical limitations to makers, from engineers to healthcare professionals. Made4You also includes private corporations, donors and co-funders to connect and provide financial contributions to fund specific solutions or kick start the production process. Made4You aims (1) to offer open healthcare solutions on a central space, where they easily can be found and shared and (2) that the solutions are **fully documented** in an open source way so citizens are able to replicate solutions in any local lab or makerspace. This open and inclusive approach is an alternative model to sustainable, affordable and personalized healthcare services.

Current open source healthcare solutions have their own dedicated platform for technical documentation and user experiences, such as *Nightscout* or *EchOpen*²⁰. As the amount and complexity of open source healthcare solutions increases, the urgency for a proper classification increases as well. Like the open source 3D printed prosthetic hand of *Enable* that contains multiple components and areas to work on such as casting of the limbs, printing of socket and fingers and the assembly process.

The knowledge, improvements and insights on all of these areas need to be included on a central platform. As Made4You is an inclusive hub for a wide variety of open healthcare solutions the classification of solutions and sub-classification of components is crucial. Therefore, Made4You draws on the expertise the renowned Fab Labs and GIG-members to align **requirements for the classification**. In an iterative co-creation process with stakeholders this classification is designed,

²⁰ <http://echopen.org/> [Accessed: July 20th, 2018]

developed and tested. The underlying platform technologies are based on the existing platform technologies of Wevolver, which has been awarded for its innovation potential²¹.

Made4You's ambition is to **increase the existing knowledge and expertise** of communities of makers, engineers and designers, and citizens, patient groups and healthcare professionals to achieve a fundamental shift in development and delivery of open source healthcare solutions. Made4You is the first project to support this paradigm shift through the integration of an online platform and physical labs and makerspaces. The approach of Made4You and the tangible outcomes differs from projects like *OpenCare*. In *OpenCare* the main focus is to engage communities with online tools that is guided by community managers. During workshops, co-creation sessions, meetups, and other interactive gatherings new open healthcare solutions are designed with the different stakeholders in an open approach to design (figures 9-12).



Figure 9 and 10: Saddle up specially made for Anna (Opendot)



Figure 11 and 12: Designers, healthcare professionals, carers and people with a care need designed and realised new healthcare solutions at MakeHealth workshop series (WAAG)

Made4You involves stakeholders directly and locally; the Fab Labs and makerspaces within the consortium function as physical innovation hubs. The use of an open standard and documentation tool enables every Fab Lab or makerspace in the world to get involved, enabling a global impact.

The proposed workshop at Design4Health 2018 is to involve designers in the field of healthcare to critically reflect on and question the potential of co-design of 'open' healthcare solutions. Thereby creating insights and increase the knowledge on 'How to increase accessibility to healthcare solutions through an 'open' design approach, using the principles of digital fabrication to produce the solutions locally with the community?' And to thrive towards the establishment of a sustainable model for open source healthcare solutions.

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Designed with Dementia: Developing Creative Communities

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ABSTRACT *This paper presents an ongoing research project situated within the investigative context of design and dementia. The work adopts an open approach to working with people living with dementia by recognizing and utilizing the inherent personal creative abilities that every individual possesses no matter their cognitive ability. Through a series of carefully developed co-design workshops, 'Designed with Dementia' supports people living with dementia to express themselves fully. Their input is highly valued and is held in the same esteem as any other collaborator. In this project, participants become collaborative designers helping to propose possibilities, evaluate and select solutions, give their knowledge and skills freely, and generally 'make things happen'. In particular, co-design is used here to engender sociable interactions and collaborations, change existing patterns of behaviour amongst all the participants, and look to change assumptions and pre-conceived ideas.*

Keywords: Co-design, Dementia, Collaboration, Creative Communities

Introduction

In the UK, dementia and how we respond to it has reached a crisis point. It is a problem that improved public awareness or a better diagnosis alone will not solve. The UK Government believes we need to see profound changes to the way we view the person living with dementia (All Party Parliamentary Group on Dementia 2016). With this in mind, the 'Designed with Dementia' co-design project presented in this paper helps to show that people living with dementia can continue to make a significant contribution to society after diagnosis. The approach taken here actively involves a range of stakeholders in the co-design process such as care workers, people living with dementia, and their family and friends to help ensure the collaborative project is valuable and useful. The co-design work presented in this paper has been carefully developed to be appropriate to people living with dementia serving emotional and practical needs by responding to their shared cultural interests. Moreover, the co-design work aims to help people recently diagnosed with dementia to build their self-esteem, identity and dignity and to keep them connected to their community. The project discussed in this paper is one of a number of ongoing projects that target these aims.

The Nature of Dementia

Dementia is a broad umbrella term used to describe a range of progressive neurological disorders. Common symptoms of dementia can include problems with short term memory where new information is difficult to retain. Everyday experiences, people and places can become unfamiliar, confusing and personally challenging. Language can become troublesome and methods of communication restricted as words and intentions become confused. People with dementia may lose interest in engaging with others socially, they may become quieter and more introverted impacting self-confidence. Amongst older people, dementia makes the largest contribution to the need for care (Prince et al. 2013). The demand for dementia related health and social care services continues to increase as a result of demographic changes. Responding to this challenge will require innovative ways of supporting people with dementia to live well from the early stages of the illness. People need support from the point of diagnosis to come to terms with this life altering illness, to remain connected to their community and enable them to live well.

Design and Dementia

This ongoing research aims to develop a number of disruptive design interventions that break the cycle of well-formed opinions, mindsets, and ways-of-doing. The idea that nothing can be done to help people with dementia often leads to feelings of hopelessness and frustration (Batsch and Mittelman 2012), perpetuating a sense of stigma, isolation, and generally negative reaction. Many people living with dementia have a sense of inadequacy and low self-esteem, with personal perceptions of their status within society reduced as a result of diagnosis (Katsuno 2005). Generally speaking, people living with dementia are not considered as contributing to UK society. Rather, they are seen as a social and economic burden. Rarely are people living with dementia deemed

capable of contributing to the UK's GDP by designing and developing new products and services. This ongoing work, however, sets out to directly challenge this assumption. A 'designing with' perspective has been applied where the person living with dementia is not viewed as a 'subject' but rather as an 'active participant' in the project (Sanders and Stappers 2014). Emphasizing fun, our approach encourages the development of richer, more varied solutions to everyday issues (Bisson and Luckner 1996). The co-design work presented here adopts a largely interventionist approach, which is based on a number of recent theories emanating from research in economics, business and design (Christensen and Overdorf 2000; Scharmer 2011; Rodgers and Tennant 2014) that celebrate jumping straight in, doing things in order to learn new things, and valuing failure.

Designed with Dementia is a design proposition that utilizes the latent creative abilities of an individual's personal knowledge and skills (Kelley and Kelley 2015). Here, people living with dementia are highly valued and their inputs and collaborations are held in the same esteem as any other party. In the process, all the participants become co-designers helping to propose possibilities, choose solutions, provide services and 'make things happen'. Co-design is predominately about 'change' (Brown 2009; Heath and Heath 2011), which relates to making a difference in the world around us. In this scenario, the actions of the designer and the people that they work with are inter-linked by collective responsibility and the desire to make a difference. In this work, the incentive for change and opportunities for co-design do not revolve around resolving the condition of dementia. Rather, this work is interested in the power of the individual, the value of their lived experience, and their continuing inclusion in society. Ultimately the purpose of this project is to do stuff with people, to try things out, and to accept occasional failings as long as action has been undertaken and the results evaluated and used to improve the next approach.

Designed with Dementia

The 'Designed with Dementia' intervention, 75BC, is an ongoing collaborative project that celebrates the life and work of the Glaswegian comedian Billy Connolly. The co-design project between the authors and a dementia support group based in Bridgeton in the East End of Glasgow involved a series of recent visits to the 75BC murals in Glasgow and to the American artist Tschabalala Self's exhibition at the Tramway Gallery, Glasgow. During this project, five people living with dementia produced a range of visual representations of Connolly using collage to create a series of textile designs in the style of Tschabalala Self (Figure 1). The artworks make use of fabric patterns originally produced in the Bridgeton area of Glasgow alongside patterns from Glasgow's wider creative community. Two forms of Billy Connolly have been used here; Big Banana Boots from early in his career and a more recent picture at Dressed to Kilt in 2011. All of the group members composed their designs and colour schemes in accordance with these two original images. Some followed a clear plan whereas others adopted a much more freeform expression in their representations. The intention of the 75BC co-design project is to use the images created by the five people living with dementia to highlight their inherent creativity and to support the 75BC celebrations.



Figure 1: Tschabalala Self artworks (top) Billy Connolly at the People's Palace (bottom) all of which were photographed by the co-design collaborators (people living with dementia)

Stage 1 introduced the group to undertaking primary research; during a visit to Tschabalala Self's exhibition at the Tramway Gallery, Glasgow the participants were given a digital camera and asked to photograph the artworks, focusing on their composition and their structure. Each participant was asked to photograph what appealed to them. The photographic investigation was rooted in a conversation the authors had with one of the participants in a previous meeting. The participant talked of his pride in his niece being a photographer and how he never had the chance to take photographs. Armed with a digital camera each, the participants set about eagerly photographing the exhibition from different perspectives, selecting what to photograph and how. One participant was particularly adamant that only two of the artworks appealed to her and those were photographed because of the vibrant background colours. Having previously visited one of the three Billy Connolly 75BC murals in Glasgow, discussions between the authors and the participants had already taken place regarding the three murals and what the group felt about them; they were not convinced the murals represented Billy Connolly as they thought of him. This discussion led to a follow-up visit to the Peoples' Palace in Glasgow in order to see the original Billy Connolly artworks and to see others that were not chosen (Figure 1).

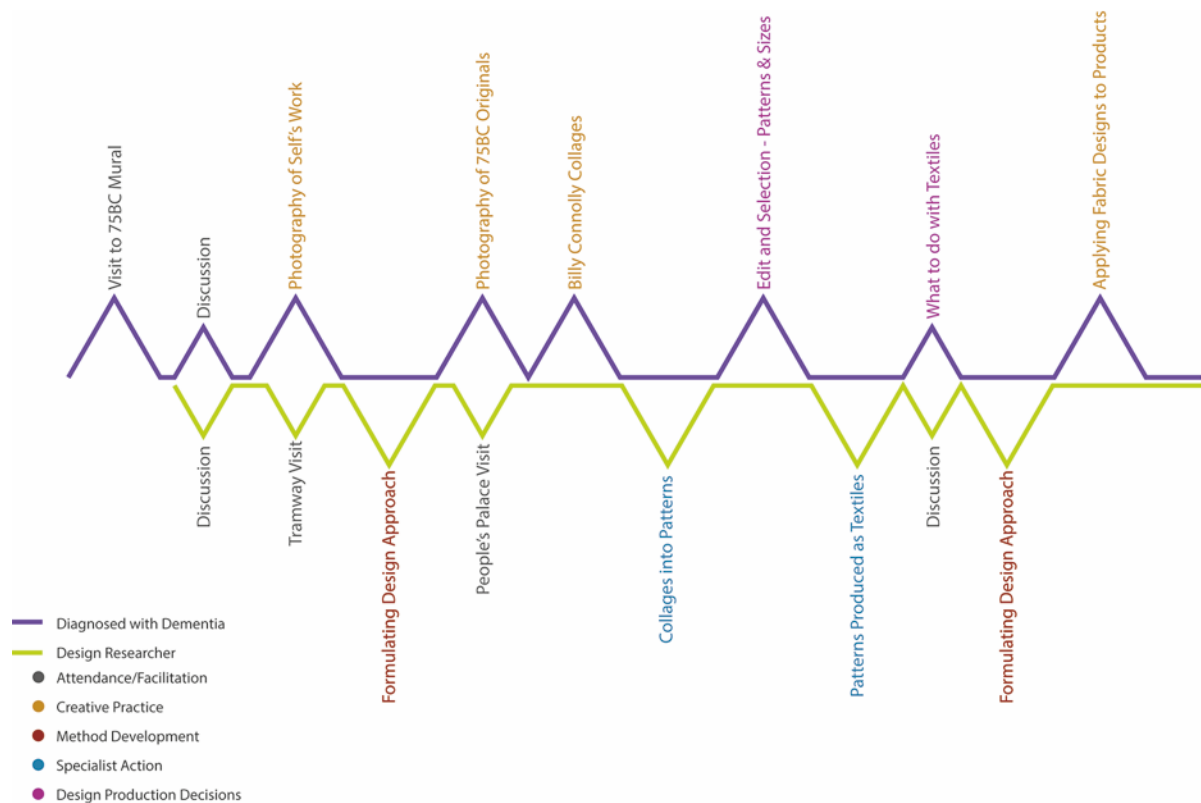


Figure 2: Diagram of the 75BC textile co-design journey

Stage 2 incorporated discussions, reviews of visits and photographs taken which informed the authors in the development of a kit for the next workshop. The process of Tschabalala Self became the inspiration for creating new visual representations of Billy Connolly. Self's layered scraps of materials stuck and stitched onto canvas create highly expressive figurative artworks. The participant photography of which, document the elements of layering, pattern and colour the group deemed important. To borrow from this approach a range of highly decorative textile patterns were selected to form the basis of a kit for making the new Billy Connolly artworks. More iconic Billy Connolly poses were then used to create collage kits where heads, legs, bodies, hands, feet and clothing were cut into small portions of pattern. Sixteen pattern variations for each part were offered to the group from which they selected the elements they wanted to use. These parts were then stuck down to make a collage of Billy Connolly. The process was open to individual participant interpretation. During the making of the individual collages, it was observed that each participant's image selection and decision making was particularly important to them. For example, one participant stressed that he wanted the right hand and right boot to match but that *'the hands and the feet shouldn't match'*. This was a clear personal choice of the participant and an articulately expressed creative decision relating to the organization and arrangement of the constituent parts. Another participant was adamant that she was not interested in making the image in the form of a human figure. Instead, she stated *'I'm waiting until everybody has got their parts and then I'm going to use the parts I want'*. After this, she then proceeded to select multiples of figure parts to create her more abstract patterns.

The outcomes from the Stage 3 consisted of multiple sheets displaying human figures collaged into patterned silhouettes along with two highly abstracted forms. Throughout the process unexpected arrangements occurred driven by individual decision making.

In this project, the co-design decisions and actions displayed the often-leading roles played by the people living with dementia illustrated in Figure 3. Here, decisions, discussions and actions have informed the direction of project. Adapting regularly to these choices, behaviours and actions the authors regularly re-evaluated the potentials of the outcomes. The applications of the visual outcomes as designs, were driven by the design conversations that occurred. On viewing the 'Big Banana Boots' images alongside the abstracted arrangements (one of many unexpected outcomes) it became apparent that the new images had the potential to become patterns in their own right. Given that textiles initially informed the project, it was by happenstance that the idea of creating a repeat textile pattern for a new local fabric was developed (Figure 3).



Figure 3: Designing the Billy Connolly figures (top) New Bridgeton textile fabric design proposals and selection (bottom)

Thus far, in this collaborative project the process of co-designing developed through the actions and reactions of the workshop participants. That is, every participant's creative input has been valued and taken into consideration throughout and achieved through mixed methods including, discussion, creation of new visuals, photography and collaboration. In the next stage, the authors responded to the designed outputs that the group had created. New arrangements were made through repeating their original Billy Connolly designs. Here, spacing between original elements and the figures was maintained in their original state. The only aspects reconfigured were the surrounding blank space and the alignment or rotation utilised to make repeating patterns.

In stage 4 the group of participants reviewed the eight patterns that had been created with a view to choosing three patterns to get produced as a printed textile. The group selected four. Here they

also agreed on the production scales for each pattern (Figure 4). These were then produced as prototypes in heavyweight cotton using a digital textile printer. In the following workshop, the group were shown the prototypes and given templates of ubiquitous household furnishings (derived from previous discussions) through which they could explore the idea of making their own home furnishing collection imbued with their fabrics.

Within the creation of the Bridgeton 75BC textile designs, individual and collective working, design facilitation and experimental practices have resulted in a series of textiles and products that are the result of a highly collaborative process. At times, it may appear that certain elements of the project directed and perhaps restricted the participants in a particular direction. However, it is fairly common in professional design practice that restrictions can help inform a designer's output. Even the designer-maker, producing items for their own collections will necessarily restrict their creative practice. In this co-design project, experimentation, conversation and serendipity played out and the ebb and flow of ideas and creativity has resulted in a truly collaborative collection of new textile designs.

This ongoing work is intended to explore how far these designed outcomes can go in the sense of production and potential sales. Ultimately, it is viewed that through exhibition and commercialization the impact of the group's work will challenge societal assumptions and preconceptions about the capabilities of people living with dementia. This project looks to take their designs into phases of wide broadcast and personal consumption in the same ways that any designer would intend to do. Though an ongoing project, the work has already formed the focus of a participatory exhibition where more than 200 participants from a cross-section of society experimented with the tools and techniques that have been utilized by the Bridgeton group.



Figure 4: The four textile fabrics (top) and the textile designs being applied to products (bottom)

Conclusions

Reflecting on this co-design work, it is abundantly clear that people living with dementia can offer much to society after diagnosis. Working closely with stakeholders including carers, family members, and collaborating organizations such as Alzheimer Scotland, the authors have received very positive feedback on this co-design work. Participants have stated that the co-design experiences had been very positive; they have been interested, engaged, and enjoyed the co-design project; there had been concentration, focus and discussion during the co-designing activities. Impact has also been seen in a number of 'spin-off' projects, discussions, themed activities and outings. The project presented here shows how co-design methods and tools can enable people living with dementia to make a significant contribution to society after diagnosis. Specifically, this work has shown how design thought and action can contribute to changing the perception of dementia and shown that whilst the mood and behaviour of the person may be profoundly affected, their personhood is not. Moreover, this co-design project has helped reconnect people recently diagnosed with dementia to build their self-esteem, identity and dignity and keep the person with dementia connected to and thinking about their local community. The widespread assumption that people living with dementia cannot take part in mainstream activities, and that they have no quality of life or capacity for pleasure and positive involvement has been dismantled by this project. While the symptoms associated with dementia affect the way a person living with dementia interacts with others, and some activities may be inappropriate as a result, there are still many activities such as designing in which they can participate. Moreover, people living with dementia should be encouraged to make decisions or partake in decisions that affect them for as long as possible to maintain their dignity and self-esteem. This has been at the heart of this project.

By the year 2030, over 80% more people aged 65 and over will have some form of dementia (a moderate or severe cognitive impairment) compared to 2010. Design, in general, and design research, in particular, needs to embrace these challenges head on.

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How Lego® Serious Play® supports team building through the creative coproduction

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ABSTRACT This case study paper will describe the process and underlying theory behind the use of Lego® Serious Play® (LSP) being used to develop a shared vision and real time strategy for the Translating Evidence to Enhance Maternal-newborn care: Knowledge Translation (TEEM-KT) team. LSP draws on a range of theories around reflection, externalizing thoughts and making tangible alongside the actual building of metaphors as a means of sharing and developing complex ideas. These theories will be discussed further in the paper in light of the authors previous work around knowledge mobilization and particularly creative practices in knowledge mobilization. In the case study described, there were 20 participants including the team lead and Research Fellow and the session was delivered by two LSP trained facilitators.

The methods were drawn from the LSP canon with preliminary skills building followed by a series of questions prompting participants to build and share. This process explored personal then collective perspectives about the current team then a vision for 3 years in the future. Short evaluation questionnaires were filled in before and after the session by all participants, asking about expectations and then how the workshop had addressed those expectations. Other results were in the form of the individual and shared models that were created and described by the teams.

Whilst LSP has been used extensively in the Business world, the authors feel it has much to offer in the world of health, not only in team and strategy building but in the broader endeavours of knowledge mobilization. It is an example of creative co-production and addresses and evidences many of the challenges of coproduction identified in the health literature.

Keywords: Lego Serious Play, Knowledge Mobilization, Play, Strategy

Introduction

The 2010 UK National Health Service staff survey identified that over 90% of individuals reported they work as part of a team, but of these only 75% claimed they had a set of shared objectives (Care Quality Commission 2010). West (2013) argues that without this shared understanding teams exist in name only. This area provides a space in which to explore how to achieve these shared objectives and allows for the application of creative practices drawn from the design in health literature. In previous work the authors have explored the potential of creative methods in enabling the coproduction of knowledge (Cooke et al. 2016; Langley, Wolstenholme, and Cooke 2018). One approach that has been used explicitly in the team context (and largely industry) is Lego® Serious Play® (LSP). We will explore the LSP approach further in the background. The team in question was already exploring Knowledge translation and using the embedded researcher approach espoused by Integrated Knowledge Translation (Gagliardi et al. 2016), and were keen to use methods to enhance coproduction of an understanding of where the team was now and where it wanted to be in 3 years. This paper will describe the application of LSP to achieve this shared understanding, its results and how the approach was received by the participants.

Background

LSP is a methodology or innovation tool originally developed by Lego®. It focuses on enabling all participants to contribute, on using construction as a way of making sense or learning (from Papert's constructionist principal –1991) and on the use of physical metaphors to aid communication of complex ideas. According to Gourlay (2002) it engages the participants on a level playing field, removes jargon, unlocks unconscious knowledge and makes knowledge and ideas tangible. Alison James discusses some of the underpinning theories of LSP in her report 'Innovative Pedagogies Series: Innovating in the Creative Arts with Lego' (James 2015). Within a Healthcare landscape, the use of LSP has largely been restricted to a corporate training tool for CEOs and senior clinical academics or managers. There are very few examples of LSP use in Health Research or Innovation.

Team KT

TEEM-KT was established in 2016 to support the translation of evidence into practice as part of the Women's and Newborn Health Program at the IWK Health Centre (IWK). The goal of TEEM-KT is to uncover effective knowledge translation (KT) interventions that support both healthcare providers' and system users' behaviour change in the Maternal Newborn setting of the IWK. This behaviour change will support the uptake and use of research evidence. Similar to the principles of Practice Development, team members describe TEEM-KT as a research program that 'allows for networking with fellow peers, graduate students, consumers, and experts in the field. TEEM-KT's goal is to

increase understanding of what roles these people play in research and inform new ways of working together’.

Method

The LSP workshop ran for a full day on the 21st of Oct 2017 in Dalhousie University, Halifax, Canada. There were 20 participants and 2 facilitators (authors 1 and 3) each taking a group of 10 participants. The participants were purposively recruited by the TEEM KT lead. They were divided into the two groups ensuring as much diversity as possible in each group. The workshop activities across the two groups were identical.

The process of LSP is ‘build and share’, at each stage all participants build a model in response to a question and then share a description of their model. The facilitator draws out further expansions on this by asking about meaning attributed to specific physical features of the models. For the ‘Big Questions’ an additional activity occurs, participants have to identify the key piece of their model that is central to their understanding or belief about the question. This piece is then placed in the centre of the table, and through a process of negotiation a shared model encompassing every individuals piece is created. This model is not a consensus model, but something all contributors can ‘live with’. This ensures that when the shared model is described everyone can see and have their contribution recognised.

All participants were asked to complete a short questionnaire before and after the workshop. The responses to these questions were transcribed and summarized. The responses were not linked to the participant, so no trends across different levels and types of staff could be explored, they were also not linked pre and post so we are unable to say how the process effected individuals directly. As a result of these limitations we are presenting a content analysis rather than a thematic analysis (Hinds and Vogel 1997), where we will report the range of responses rather than any deeper exploration of underpinning themes.

Results

The results will be discussed in two sections:

Outputs from workshop: The two ‘big questions’

Participants were asked to respond to the statement ‘describe what TEEM-KT is to you?’ LSP questions work better when they are broad and asking for a personal perspective as it allows participants to explore a broader range of responses, has no wrong answers and build metaphors rather than a model that responds to a certain requirement. After building and sharing the first model they responded to ‘describe how people outside this team see TEEM-KT’.

As described above there followed a process of Negotiating a shared model that describes 'what TEEM-KT is now' using the key piece of either the internal or external perspective models already built.



Fig.1 Group 1 image of now, keywords: *opportunity, academia, innovation, women's health, noise*



Fig 2. Group 2 image of now, keywords: *teamwork, goal: improvement, connections, unaware, viewpoint*

The two 'now' models both contained self-critical elements such as 'barriers' and 'screens' between team members and between the team and others outside. These are picked up and expressed in the key words 'unaware', 'viewpoint' and 'noise'; noise being a reference to a dismissive description of the work going on in TEEM-KT by some outsiders. They also contained critical reflections on the systemic structures within which they worked as expressed by the keyword 'Academia' depicted by the black structure at the top edge of the grey plate in figure 1. Academia was described as both a negative and positive factor in this image of TEEM-KT now.

The participants saw their subject matter (Maternal and Newborn health) and their own gender (all women) as a real strength of TEEM-KT. They were proud of being mothers themselves and successful women, academics and clinicians. They believed their gender gave them strengths in their teamwork and peer to peer support, captured in the keyword 'Women's Health' depicted by the two colorful and creative towers bridging the blue and grey plates in figure 1.

They also expressed a very clear purpose or goal in the key words 'innovation' and 'improvement'. These broadly captured notions of knowledge translation or 'getting research used' but at the same time encompassed a slightly messier, incremental reality to this.

Finally, there was an expression of a couple of the mechanisms by which TEEM-KT worked in the key words 'opportunity' and 'connections'. It was seen as an important element of the work TEEM-KT did to make personal connections and to seize opportunities.

The second 'Big question' was to build a model to describe 'what TEEM-KT should look like in 3 years'. This again was built as individual models, shared and then the key piece identified. The process of Negotiation into a shared model followed with the models and keywords below



Fig. 3 Group 1 image of 3 years time, keywords: *sustainable, diffusion, impact, collaboration, vision*

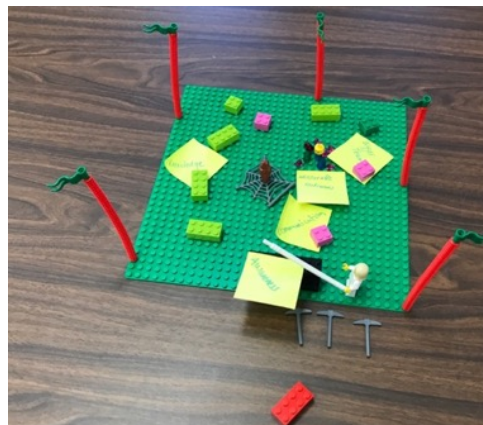


Fig 4. Group 2 image of 3 years time, keywords: *knowledge, awareness, communication, measurable outcomes, bigger team*

The two models of '3 years' contained practical details of what would have to be done to allow TEEM-KT to be sustained. For example, '*communication*', '*measurable outcomes*', '*impact*', '*bigger team*'. There was a recognition that being able to communicate the clear vision for the team both internally and externally was central to the ongoing success of the collaboration in '*vision*' and '*awareness*'. These goals were to be taken forward in subsequent practice development work by TEEM-KT.

Pre-post evaluation:

1. What are your expectations for the day?

A range of responses in two broad areas, one having no idea what was going to happen and therefore little or no expectations and the other hoping it would be a fun and engaging, 'Have fun! Laugh a lot! Learn! Build relationships! Create a shared vision for research!'.

2. How are you feeling at the beginning of the day?



Fig 5 word cloud of participants' feelings at the beginning of the day

3. What do you think about Lego as a team building exercise?

There were a range of responses some very positively disposed to the idea of using Lego, 'I love Lego, so it has to be good' to others who had a more considered response and were interested to see how the day would pan out.

After the workshop a further set of questions was asked.

1. Did this day meet your expectations?

13 of the respondent said that the day met or exceeded their expectations, the only cautious responses were around the form of the outputs for the day and how the learning would be taken forward, 'In part- was hoping to have more concrete actions forward. Great for building relationships with others.'

2. How are you feeling at the end of the day?



Fig 6: word cloud of participants feelings at the end of the day

3. What went well today?

Participants reflected that the chance to work together facilitated with tools that ensured everyone could contribute was very powerful, 'Able to go beyond self and focus clearly on others ideas as well as my own- Great sharing'

4. What could be improved upon?

Participants responded to say they wished the day had been a little shorter, and that there had been the opportunity for the two groups to be mixed up throughout the day.

5. What do you think about Lego as a team building exercise?

Respondents were universally positive, although some more cautiously so, many reflected that it could have other applications outside of the team building purpose of the day, 'Actually makes me wonder what other applications are possible.'

Discussion

We have described the outputs of the LSP workshop that was set up to support building a shared vision and goal for an innovative research grouping. Participants appeared to agree that the workshop had allowed this to happen, but we have to recognize some caveats around the success in this specific case, before considering the approach more broadly.

The pre-workshop evaluation data appears to demonstrate either a general reservation of judgement or that participants approached the day expecting the process to be 'fun'. There was also curiosity to see how Lego, which many people know predominantly as an enjoyable toy, would be used in a work setting. Even though as facilitators authors 1 and 3 are mindful to use the full title Lego Serious Play, few participants believe that it will be serious, and so this can set up a bit of a mismatch of expectations (James 2015).

The issue of outputs and next steps has been noted by the facilitators previously, and a range of approaches applied to capture the learning from workshops. This point has not been commented

on in other literature about the use of LSP in business or in teaching and therefore maybe unique to academics associated with their need to document, record and report; 'knowledge can only exist if it is written down'. In this case the shared models were photographed and participants encouraged to write post-its of their key themes. This doesn't really sit comfortably with the capture of rich and complex understanding gained from the metaphors. Subsequent workshops have used video to record the visual and audio descriptions of shared models, these are edited, curated and shared back to all participants for a prompt to both remember and provoke further reflection.

The length of LSP workshops continues to be a contentious. It is a compromise between allowing the workshop to get to the output stage against the emotional labour of participating in the workshop. The tiredness seems to come from people having to think, and listen in very different ways to their normal day (James 2015). We have had more success splitting the workshop over two days.

The engaging nature of the media and the process along with its approach to inclusion and valuing all perspectives was appreciated by the group both in the context of their own team and in their insights into how it might be usefully applied in other areas.

The recognition that LSP might have other uses outside of team building or real time strategy is not new, and is in fact the reason author 3 first commissioned the training. We are building up a range of case studies of the approach which will be addressed in subsequent papers.

Conclusion

As mentioned in the introduction authors 1 and 3 are largely concerned with the processes that are described as knowledge mobilization, and see LSP as a powerful method for sharing knowledge eliciting tacit personal, organizational and system knowledge and blending knowledge between stakeholders (Kristiansen, Hansen, and Nielsen 2009).

Knowledge mobilization used to be about getting (largely) research knowledge in the form of the outputs of research, into practice. This was described as mode 1 knowledge mobilization or knowledge transfer and suggested that the only thing stopping research being used in healthcare was a lack of awareness of the 'right' thing to do (McCormack et al. 2002). This conceptualization has moved forward to mode 2 which is about trying to bring different forms of knowledge (e.g. Research, tacit, Know-how) together in new shared understandings to deliver benefit for all stakeholders in health with an explicit recognition of the importance of context. Mode 2 preferences a broader range of types of knowledge, recognizing that what is important is not just the 'how' but the 'how we do it here' aspects of experiential knowledge (Rycroft-Malone et al. 2016). In this paper we refer to Mode 2 as coproduction.

Coproduction is not straightforward to achieve and, in her paper, Greenhalgh sets out factors that have to be in place for successful co-creation to take place, namely;

‘a systems perspective, a creative approach to research focused on improving human experience, and careful attention to governance and process.’ (2016, 392)

In previous work the authors have described how through ‘collective making’ many of these conditions are satisfied (Langley, Wolstenholme, and Cooke 2018), and one of the exemplars of these approaches was LSP. We would argue that LSP encourages a broader, systems type view across issues by enabling all stakeholders to have equal input into the exploration and by eliciting some of the tacit system knowledge that different stakeholders unconsciously possess. Creativity and the careful attention to governance and process are enshrined in the LSP approach and through making thoughts and feelings tangible through physical metaphors, allows a different relationship with one’s self and with others.

This ability to develop a shared understanding, through mobilizing different forms of knowledge allowing a real time synthesis, responds to West’s (2013) challenge to teams and speaks to a broader application of such methods to other aspects of design and health research and practice.

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Co-designing mobile help-seeking toolkit with young people: An Australian case study

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ABSTRACT ONLY *Online mental health services that use digital health promotion technologies to promote youth wellbeing in Australia are undergoing rapid and critical change in models of service delivery. In Australia 89% of young Australians own a smartphone and 83% downloaded an app in the first quarter of 2013 making help-seeking services that do not utilize the affordances of mobile technology increasingly limited. Australian youth counselling and outreach services are making a gradual transition to evidence-based, technology-enabled solutions. Evidence of high demand for and limited access to established online services adds pressure on service providers who face an ever-increasing technology gap between the technological affordances of their online services and young people's rapidly evolving digital literacies, including how they engage with and assimilate health information. Little is known, however, about the impact of these self-help resources on young people's wellbeing or how these self-directed resources integrate with current counselling modes.*

This indicates a potential for the design and development of an alternative service model that utilizes mobile technology as the main platform for access to standalone resources, as well as the possibility of live counselling.

This paper reports on the design process and outcomes of a nationally funded research project conducted in collaboration with Australia's largest youth counselling service, and resulting in a mobile app iteratively co-designed and tested with three groups of young people (aged 12-15yo, 16-19yo, and 20-25yo) and youth counsellors, providing a digital solution that is standalone while integrated with an existing service, and pointing to an alternative model for engaging young people in help-seeking. The app was developed using a mixed methods approach, including qualitative and participatory design research methods, resulting in a preliminary tested digital prototype. Outcomes of this transdisciplinary research – and the integrated model of service delivery – have the potential to inform future service design targeting young people and importantly, the significance of involving young people directly in co-designing the solution.

Keywords: Young people, technology, participatory design, help-seeking, Australia, national service

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